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Guest editorial

The role of public health in the health of Canada's children

Dr. David Butler-Jones, Chief Public Health Officer

Although Canadians are among the healthiest people in the world, some groups of Canadians are more likely to experience poorer health and premature death than others.[1] In general, health status follows a step-wise gradient where people in less advantageous socio-economic circumstances are not as healthy as those at each subsequently higher socio-economic level.[2] Those with the lowest incomes and education, in combination with other related factors – inadequate housing, poor working conditions, detrimental health behaviours, limited access to health care, and who lack early childhood support and/or social supports – are more likely to develop poorer physical and mental health outcomes than those living in better circumstances.

Canada has strong social policy foundations that have helped to make it more egalitarian, and thereby, healthier. Programs like the Canada and Quebec Pension Plans, Old Age Security, Employment Insurance, publicly funded health care and universal primary and secondary education have all helped to establish a minimum standard of living. However, after 20 years of declines, income inequality has increased in Canada over the last decade.[3]

Two papers in the current issue of *Chronic Diseases in Canada* highlight the importance of social and economic factors as determinants of children's health. The paper by Gagné and Hamel[4] reported that children in the most materially deprived areas of Quebec had significantly higher risk of hospitalization from transportation-related injuries and from poisonings and fires. Risks for sports injuries, however, were lower for the most disadvantaged. A similar, but more modest risk gradient was observed according to measures of social deprivation.

Determinants such as the natural and built environments create the context for other determinants of health such as income, employment, social networks and personal behaviours. In terms of injury prevention, community design features such as recreational pathways and sidewalks, safe levels of lighting, and compatible land uses can ensure pleasant, safe spaces for both recreational and transit activities. The absence of safe streets and recreational areas influence the risk of injuries. Moreover, social and economic factors in deprived neighbourhoods, such as household structures, can also play a role in the risk of childhood injuries.

Dr. To and colleagues reported that low income adequacy was associated with higher rates of hospitalization, but lower rates of doctor visits for asthma, among children with asthma,[5] suggesting poorer outpatient management of asthma among children with low income adequacy. While Canadians take justifiable pride in their universally insured health care, income still plays a role in medical access to specialists[6] such as respirologists. Socio-economic differences in asthma medication use, which contributes to appropriate asthma management, may have also contributed significantly to the differences in asthma hospitalizations by income.

Understanding the causes of these inequalities and developing interventions that reach these groups are essential elements of public health action.[7] It is not enough to focus solely on individual health choices and behaviours, as peoples' actions are very much shaped by the social and environmental conditions in which they live and work. A balanced mix of targeted interventions for high risk populations and universal programs for all is more likely to work in a country as vast and complex as Canada.[1, 8,9] This kind of balance ensures that, regardless of personal circumstances, Canadians experience those conditions necessary for better health and for making healthy choices the easier choices.

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Guest editorial

From rags to genes: mixing research paradigms

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The journal is publishing two papers[1,2] in this issue that underscore the contribution of social and economic determinants to outcomes such as hospitalization and the use of health services among children with injuries and asthma. Both papers show that greater use of health services is generally associated with lower economic status and, though not as markedly, with social status as well. These observations are taking place in Canada where there is universal access to health care. Other findings are also of interest; for example, the To et al. study[1] reports that, whereas children from low-income families were at higher risk of hospitalization regardless of severity of asthma status, they had lower utilization of physicians' services. On the other hand, children with persistent asthma were less likely to come from low-income families or to be born to immigrant mothers. In addition, children of immigrant mothers were less likely to be hospitalized. The Gagné and Hamel study[2] may have used a finer definition of social and economic status, captured by two, distinct ecological variables. This study shows that both material and social status influence not only hospitalizations in children with injuries, but also the occurrence of injuries.

From a research perspective, a number of issues lend themselves to discussion based on these papers: (1) the sustained importance of accounting for social and economic status (hereafter referred to as SES) when studying determinants of health and the utilization of health services; (2) the methods used to measure SES; (3) the use of administrative or research databases for research; and (4) the way that SES influences health outcomes.

We are without a doubt in an era in which "gene-talk" has powerfully come to dominate biomedical research. The technology used to study population genetics is evolving so rapidly, is so complex, and the arguments in favour of a major role for genetic risk factors in complex outcomes are so powerful that the role of SES may be seen as remote and insignificant by comparison. However, arguments could easily be made that (a) once genetic variants are found to be associated with diseases or conditions, it does not necessarily mean that we understand how they work; and (b) the role of these genetic variants is most likely influenced by and linked with a number of environmental factors. Given the picture obtained from the studies discussed above, the same conclusions about SES factors could be reached. Thus, the complexity of SES as a determinant of health and the utilization of health services is such that, as with genetic research, SES research deserves resources. It should also involve outstanding methodological advances and remain among public health research priorities. However, prudence is warranted when advocating more and better research in this area based mainly on the assumption that SES can be acted upon, in comparison with other determinants. Changing SES may be as difficult or even more so than developing gene therapy!

What direction should research in this area possibly take? Given the assumption that genes and related physiological mechanisms are turned on and off by our environment, SES factors included, and that researchers in one area may be less than highly competent in the other, initiation of a dialogue between the biological and public health/sociological research communities would be a very useful approach to better understand both types of determinants. It could potentially lead to outstanding findings, such that the results are also better understood. Whereas it is probably relatively easy to agree that the pathways to injuries and asthma are both genetic and environmental, it may be more difficult to become convinced that similar pathways influence the use of health services. However, it does remain plausible, although possibly even more complex, and with different weights for different determinants.

The authors of both papers in question efficiently used available databases (administrative or research-oriented) to pursue their analyses, as well as measures of social and economic determinants that, although useful and acceptable, were likely limited, due in part to the constraints of database research. As a result, the reported findings may give an impression of "déjà vu," and definitely leave many questions from apparently contradictory findings, either within the studies themselves or between these and previously published ones. However, the authors had descriptive goals, which they properly pursued. Such results are of high interest to this journal and they are welcome; it seems particularly opportune for the public health community to use available databases of good quality. However, we would also like to encourage other innovative and bold approaches, the use of more refined methods to measure SES, and alliances with the biology community to better understand the factors at play in health and the utilization of health services.

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Health outcomes in low-income children with current asthma in Canada

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Abstract

Data collected from the Canadian National Longitudinal Survey of Children and Youth (NLSCY) in 1994/95 and 1996/97 were used to measure longitudinal health outcomes among children with asthma. Over 10 000 children aged 1 to 11 years with complete data on asthma status in both years were included. Outcomes included hospitalizations and health services use (HSU). Current asthma was defined as children diagnosed with asthma by a physician and who took prescribed inhalants regularly, had wheezing or an attack in the previous year, or had their activities limited by asthma. Children having asthma significantly increased their odds of hospitalization (OR = 2.52; 95% CI: 1.71, 3.70) and health services use (OR = 3.80; 95% CI: 2.69, 5.37). Low-income adequacy (LIA) in 1994/95 significantly predicts hospitalization and HSU in 1996/97 (OR = 2.68; 95% CI: 1.29, 5.59 and OR = 0.67; 95% CI: 0.45, 0.99, respectively). Our results confirmed that both having current asthma and living in low-income families had a significant impact on the health status of children in Canada. Programs seeking to decrease the economic burden of pediatric hospitalizations need to focus on asthma and low-income populations.

Keywords: *asthma, low-income, hospitalization, health services use*

Introduction

Asthma has been determined to be the most common reason for preventable hospitalization in children.[1-4] It is generally agreed that asthma is an "ambulatory care sensitive condition," i.e. good outpatient management should result in decreased hospitalizations.[5] Inadequate control of asthma can be costly; it has physical consequences and can lower a person's quality of life. In 1998, the major direct health care costs (hospital care and drug expenditures) for asthma totalled over $402 million.[6] According to the Institute for Clinical Evaluative Sciences report by To et al., the total annual indirect and direct costs were reported to be $676 per Canadian child with asthma in 1995.[7] The largest single component was hospital admissions, accounting for 77% of the total cost. The use of other health services (i.e. visits to general practitioner, specialist and emergency department) contributed 21% to the total cost.[8]

Most information on HSU and health outcomes among children with asthma is ascertained from cross-sectional surveys or administrative records.[9,10] To our knowledge, no systematic longitudinal survey data based on a population have been collected to ascertain the prevalence of asthma in various age groups, their HSU and asthma-associated morbidities. The NLSCY, a longitudinal Canadian population-based survey, provides a unique opportunity to study childhood asthma prospectively and obtain stable estimates of asthma prevalence. Specifically, the asthma status ascertained longitudinally provides us with a means to delineate the "*persistent*" asthmatics from the "*transients*," and to evaluate prospectively the impact of factors present during the preschool years on outcomes in school-aged children. The three main purposes of this study are to create a population-based longitudinal cohort of Canadian children with current asthma; to measure their HSU and health outcomes compared to children without asthma; and to assess the impact of asthma on HSU and health outcomes in children, adjusting for other risk factors.

Methods

Data source

Longitudinal data from the NLSCY cycle 1 (C1) 1994/95 and cycle 2 (C2) 1996/97 were used in this study. The NLSCY is a prospective longitudinal survey designed to measure child development and health.[11,12] A multi-stage clustered sampling scheme was used in the survey for the study sample to be representative of the Canadian population of children. The clusters were designed to have sufficient sample sizes within large geographic areas and within seven key age groupings. Trained interviewers from Statistics Canada went to households and administered standardized questionnaires to the person most knowledgeable (PMK) about the child, i.e. the biological mother in 89.9% of cases. The overall response rate to the survey was 86.4% for C1 and 91.6% for C2. Informed consent was obtained from the legal guardians and/or the child, as appropriate. A full description of the NLSCY is available

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at http://www.statcan.ca/bsolc/english/bsolc?catno=89F0078XIE[11]

The NLSCY was comprised of all children sampled for C1 in responding households. Although some children who were participants in C1 did not participate in C2 for a variety of reasons (e.g. random deliberate attrition to decrease sample size, loss to follow-up, or the biological parent not completing the survey), efforts were made to keep the number of these children to a minimum so that the longitudinal research by age cohort at the national level was still permitted.[12] Included in the analyses for the current study were a total of 10 148 children (i.e. a weighted sample of 3 128 645), aged 1 to 11 years at baseline (C1), whose biological parent had responded to the survey and who had complete data on asthma status in both cycles.

Definition of current asthma

Current asthma was ascertained if the PMK reported an asthma diagnosis in his or her child by a health professional and at least one of the following: 1) the child took prescribed inhalants on a regular basis; 2) the child had wheezing or whistling in the chest or had an attack of asthma in the previous 12 months; or 3) the child's asthma prevented or limited participation in school or other normal activities.[13] The asthma status in cycles 1 and 2 was further categorized into four groups: 1) "*no asthma*" (i.e. no current asthma in either cycle); 2) "*new asthma*" (i.e. current asthma in C2 only); 3) "*transient asthma*" (i.e. current asthma in C1 only); and 4) "*persistent asthma*" (i.e. current asthma in both cycles). The only children included in our longitudinal analysis were those categorized as having "*persistent asthma*" (PA) or "*no asthma*" (NA) (based on a total of 9 462 children or a weighted sample of 2 908 136). In the longitudinal multivariable analysis, the health outcomes of each child over time were examined using the General Estimating Equation (GEE) Model[14-17] incorporating current asthma status in both cycles while considering the correlation within individuals.

Outcome measures

Health outcomes included parental reports of child hospitalization and their HSU at both C1 and C2. Hospitalization was defined as an overnight stay in the hospital in the past 12 months. HSU was defined as help/advice the parents sought from a physician about a child's health, and was determined by the PMK's response to the question: "*In the past year, how many times have you seen or talked about your child's health with a physician?*" Both hospitalization and HSU were coded as dichotomous variables (i.e. yes/no) to minimize the impact of recall bias.

Risk factors

Other independent variables examined for potential confounding included sex, age, maternal and child health status, child chronic conditions, child history of wheeze, parental smoking, maternal history of asthma, maternal symptoms of depression (not previously examined in relation to hospitalization and HSU in asthmatics), markers of socio-economic status (SES) and maternal immigration status.

Child health status was based on the mother's rating of the child's health (i.e. excellent/very good or good/fair/poor). The child's health conditions were recorded if the PMK reported a diagnosis of allergies or bronchitis by a physician. Wheezing or whistling in the chest at any time in the last 12 months characterized the child as having wheeze.

Maternal health status was based on her self-rating of health (i.e. excellent/very good or good/fair/poor). Parental smoking was based on whether cigarettes were smoked daily, occasionally or not at all.

Income adequacy was classified into low-, middle- and high-income groups based on total household income and the number of household members.[11,18] A child's mother was considered an immigrant if she ever reported having immigrated to Canada. The child's age was measured by year and kept as a continuous variable.

Statistical analysis

GEE[14-17] for categorical longitudinal data was used to incorporate "time-dependent" covariates in modelling predictors of HSU or hospitalization. GEE was used to account for the longitudinal effects of the predictors on HSU or hospitalization in C1 and/or C2. Data on predictors collected in both cycles were used to measure the overall adjusted probability of HSU or hospitalization. The carry-over effects (i.e. the effect of a risk factor in C1 on HSU or hospitalization in C2) were also considered.

The data publication guides by Statistics Canada were followed.[11,12] Longitudinal sample weights derived by Statistics Canada[11,12] were applied in analyzing study population characteristics so that the derived estimates could be considered representative of the total population of children aged 1 to 11 years at baseline. Coefficients of variation derived by Statistics Canada[11] were used to determine the quality of the estimates. Accordingly, estimates that did not meet the Statistics Canada criteria were flagged.

For multiple variable analyses, standardized sample weights were used to preserve the original sample size, thereby avoiding an overestimation of significance while maintaining the same distributions as those obtained when using population weights.[19] Only statistically significant variables ($p < 0.05$) or known confounders such as sex, age, LIA and maternal immigration status were included in the final models.[20] The correlations between the covariates were examined. The SAS statistical package (i.e. SAS version 8.0, Cary, North Carolina, USA) was used for all analyses.[21]

Results

Demographics/characteristics

Table 1 shows the overall prevalence of asthma, hospitalization and HSU by the four categories of asthma status. The overall prevalence of reported asthma was 8.4% in C1 and 9.4% in C2. Using our previously defined asthma classification scheme, 4.0% had new asthma, 3.0% had transient asthma and 5.3% had PA. Overall, 87.6% of children had NA in both cycles. The prevalence of hospitalization was the highest in children with PA in both cycles (i.e.

16.8% and 8.3%) and lowest in children with NA. Compared to the NA children, the hospitalization rate was four times higher in children with PA (i.e. 16.8% vs. 3.8%; $p < 0.0001$); their HSU was also higher (i.e. 95.3% vs. 80.3%; $p < 0.0001$).

Table 2 shows a comparison of baseline characteristics between the NA children and those with PA. Overall, in children with PA, there was a higher percentage of boys aged 1 to 11 years compared to girls (i.e. 62.6% vs. 37.4%; $p < 0.001$). Children aged 9 to 11 years had the highest prevalence of PA compared with children aged 1 to 4 years and 5 to 8 years (i.e. 6.8% vs. 4.2%; $p < 0.001$ and 6.8% vs. 6.6%; $p < 0.001$). At baseline, the NA children reported better health status than those with PA (i.e. 91.8% vs. 61.0%; $p < 0.001$). More children with PA were hospitalized (i.e. 16.8% vs. 3.8%; $p < 0.001$) and used health services (i.e. 95.3% vs. 80.3%; $p < 0.001$) when compared with the NA children. Furthermore, children with PA had a higher percentage of allergy (i.e. 45.0% vs. 11.8%; $p < 0.001$) and a lower percentage of mothers who were immigrants (i.e. 13.9% vs. 18.8%; $p < 0.001$).

Estimates of HSU and hospitalization

Our regression model in Table 3 showed that being younger with current asthma (OR = 2.52, 95% CI: 1.71, 3.70) or not having excellent or very good current health status (OR = 3.10, 95% CI: 2.38, 4.03) increased the risk of hospitalization; however, a child whose mother is an immigrant (OR = 0.65, 95% CI: 0.43, 0.98) decreased the child's risk of hospitalization. However, a child's being younger, having asthma (OR = 3.80, 95% CI: 2.69, 5.37), having allergy (OR = 1.61, 95% CI: 1.33, 1.94) and not having a very good or excellent current health status (OR = 1.56, 95% CI: 1.27, 1.92) increased the risk of HSU.

The carry-over effects of the covariates were examined. Among all covariates studied, LIA showed a statistically significant carry-over effect on hospitalization and HSU (OR = 2.68, 95% CI: 1.29, 5.59 and OR = 0.67, 95% CI: 0.45, 0.99). This indicates that LIA, as measured at baseline, had lasting effects on the hospitalization and HSU in C2. Cross-sectional logistic regression analyses using the same risk factors at baseline were also explored and similar results were obtained (results not shown).

Discussion

Results from this longitudinal population-based study quantify the magnitude of hospitalizations and HSU in children with current asthma. Our findings support the hypothesis that childhood asthma has a significant impact on the risks of all-cause hospitalization and HSU. Few previous studies have examined this relationship in children. Chen et al. reported that among Canadians aged over 12 years, asthma was a significant risk factor for overall hospitalization, and that the odds ratio for asthma differ by socio-demographic variables, such as age and household income.[22] These findings were based on cross-sectional survey data and did not take into account the potential changes in asthma status over time. In the current study, asthma status was assessed longitudinally, both at baseline and follow-up. A major strength of this study was the ability to examine the temporal relationships between risk factors and health outcomes, and assess children who are persistently asthmatic or non-asthmatic over time. Children with persistent asthma had almost triple the risk of hospitalization and quadruple the risk of HSU compared to those with no asthma. The longitudinal nature of this study makes the results more powerful, as the analysis incorporated the risk factors and outcomes over time while taking into account the correlation within individuals between baseline and follow-up.

Our study showed that children from low-income families were at higher risk for hospitalization over time regardless of asthma status, yet they had lower HSU. Interestingly, other Canadian studies have shown similar findings, especially in hospitalization. A study conducted in Manitoba showed that children aged 0 to 19 years in the lowest income quintile were three times more likely to be hospitalized than those living in the highest income quintile in 1999.[23] The Canadian Institute of Child Health also reported a similar trend in hospitalization by household income among children.[24] A recent study in children born in a major Canadian urban centre found that the relationship between socio-economic disadvantage and hospitalization for ambulatory care-sensitive conditions (with asthma being the most frequent diagnosis) and all-cause hospitalization was large, consistent across many conditions, remained stable over time and persisted up to 9 years of age.[25] Since Canada has a universal health care system, access barrier to health care due to affordability cannot account for these differences. Factors leading to higher risk of acute care use among children in the lowest socio-economic stratum may include higher disease prevalence, increased disease severity, multiple comorbidities, poor health habits, crowded living conditions, inconsistent patterns of preventative care, nutritional problems and poor physical fitness.[25,26] Moreover, socio-economic differences in the use of inhaled corticosteroids have been reported in children with asthma.[27-30] Although detailed information on asthma medication use is not available in the current study, it could have contributed significantly to the differences in asthma and asthma-related hospitalizations, which account for a significant proportion of the overall morbidity in the asthma population.[31] Finally, health system factors such as distribution of specialist care may also contribute to the differences in health outcomes. It has been reported that in Canada, general practitioner care is distributed fairly equally by income according to needs; however, people with higher incomes are significantly more likely to seek specialist care than those with lower incomes, making total doctor utilization somewhat higher in the rich.[32]

Our finding on the distribution of asthma by socio-economic status (SES) is also interesting. We found that children with persistent asthma were less likely to come from low-income families. This means that the effect of asthma as a risk factor for health care utilization could be confounded by the effect of low income; however, this potential bias was minimized by adjustments in multivariable analysis. Previous evidence for the distribution of asthma by SES is mixed, and findings varied depending on the definition of asthma and the study design. Cross-sectional survey studies in the US found that SES was associated with increased asthma prevalence in

TABLE 1

Prevalence of hospitalization and health service use by asthma status

			Hospitalization		Health service use	
			(Cycle 1) (n = 147 800)	(Cycle 2) (n = 116 000)	(Cycle 1) (n = 2 562 300)	(Cycle 2) (n = 2 341 300)
Asthma status	n*	%	%	%	%	%
Persistent asthma	166 600	5.33	16.77	8.29	95.27	91.45
New asthma	126 000	4.03	6.07	5.84	89.84	92.94
Transient asthma	94 600	3.02	9.41	4.75	93.78	76.72
No asthma	2 741 500	87.62	3.77	3.29	80.32	73.03

* The number of children is weighted and values are rounded to the nearest 100; the unweighted n = 10 148.

TABLE 2

Characteristics of study population by asthma status

	Total (n = 2 908 100)*	Persistent asthma (n = 166 600)	No asthma (n = 2 741 500)
Baseline (cycle 1) characteristic	%	%	%
Sex			
male	50.54	62.58	49.81
female	49.46	37.42	50.19
Age in years (row %)			
1 to 4	37.87	27.62 (4.18)	38.50 (95.82)
5 to 8	35.14	40.46 (6.60)	34.81 (93.40)
9 to 11	26.99	31.92 (6.78)	26.69 (93.22)
Child with wheeze	13.69	85.22	9.34
Child with allergy	13.69	44.98	11.79
Child current health status			
excellent or very good	90.06	61.01	91.82
good, fair, or bad	9.94	38.99	8.18
Low income adequacy	9.77	6.94 †	9.94
Immigrant mother	18.56	13.92 †	18.84
Biological mother with asthma	4.78	15.45	4.14
Health service use	81.18	95.27	80.32
Hospitalization	4.51	16.77 †	3.77

* The number of children is weighted and values are rounded to the nearest 100; the unweighted n = 9 462. Percentages are adjusted for missing data and may not total to 100 due to rounding.

† The coefficient of variation is between 16.6% and 33.3%, which is considered marginal by Statistics Canada.

TABLE 3

Adjusted odds ratios for hospitalization and health service use based on longitudinal logistic regression*

Risk factors	Hospitalisation				Health service use			
	OR	95% CI		p-value†	OR	95% CI		p-value†
Male sex	1.25	0.99	1.57	NS	0.96	0.85	1.08	NS
Age (per 1 year increase)	0.91	0.88	0.94	< 0.001	0.84	0.82	0.85	< 0.001
Child current asthma	2.52	1.71	3.70	< 0.001	3.80	2.69	5.37	< 0.001
Child allergy	1.30	0.95	1.78	NS	1.61	1.33	1.94	< 0.001
Child current health status (good, fair, or bad)	3.10	2.38	4.03	< 0.001	1.56	1.27	1.92	< 0.001
Low income adequacy	1.54	0.91	2.61	NS	0.58	0.44	0.76	< 0.001
Low income adequacy carry-over effect	2.68	1.29	5.59	0.008	0.67	0.45	0.99	0.046
Immigrant mother	0.65	0.43	0.98	0.039	1.06	0.88	1.28	NS
Cycle 2‡	1.01	0.79	1.29	NS	0.87	0.78	0.98	0.019

CI: confidence interval; OR: odds ratio; NS: not significant (at $p < 0.05$).

* Based on unweighted n = 9 462.

† Based on longitudinal logistic regression using normalized weights.

‡ Controlled for time in both cycles.

children.[33,34] In Ontario, a longitudinal population-based study using health administrative data showed that neighbourhood income had no impact on the distribution of asthma persistence in school-age children after adjusting for other risk factors.[35]

The influence of immigration status is also important to examine given that Canada has a high immigration rate and the immigrant population may be viewed as vulnerable. Our results showed that children with persistent asthma were less likely to be born to immigrant mothers. This agrees with studies from the US and other countries[36-39] and adds to the documentation of the importance of immigration and acculturation in the development of asthma and allergy. The lower reported asthma prevalence in the immigrant population[40-42] may be explained by immunoprotection as a multifactorial phenomenon, the health-selection involved in the immigration process and the potential reporting bias due to language barriers and cultural differences. Our study also found that children with immigrant mothers are less likely to be hospitalized. This is consistent with a recent study conducted by Quah et al. using the 2001 Canadian Community Health Survey, which showed that hospitalizations among visible minorities (81% were immigrants) in Canada were lower than among white Canadians.[43] The lower rate of hospitalization also may be partly explained by the good health status of immigrants, rather than poor access, thus highlighting the unique health patterns among them.

Canadian studies using administrative data have examined the seasonal patterns of asthma hospitalizations in the province of Ontario from 1988 to 2000.[44,45] Children aged 0 to 4 and 5 to 9 years accounted for the highest hospitalization rates. Furthermore, young males were hospitalized at a rate of two to three times that of females of the same age,[44,45] a finding consistent with our results. A downward trend in the total number of hospitalizations in the general population, most notably among young males has been reported since the early 1990s.[44,45] Our study also showed that hospitalizations among children with persistent asthma almost halved from 1994/95 to 1996/97 (i.e. 16.8% vs. 8.3%). Among children participating in both cycles, the percentage of children who were hospitalized in 1996/97 decreased from 1994/95 figures, while the number of children diagnosed with asthma increased during the same period. This trend may be explained partially by the aging of the cohort between the two time periods, but may also reflect improvement in asthma therapy and changes in health care practices that have resulted in decreased hospitalizations overall.

Some limitations were present in this study. First, as in all studies based on survey data, information on health care utilization was reported by parents and is subject to recall bias. There was a risk of undercounting hospitalizations given that a child who was hospitalized on numerous occasions was counted only once in each year; in addition, hospitalization was defined as admission for any reason, and not just for respiratory illnesses. However, the consistency between the decreasing trend in hospitalization observed in the current study and that previously reported validates our findings. HSU was defined based on the question, "*In the past year, how many times have you seen or talked about your child's health with a physician?*" This question may bias the number of consultations with physicians by double counting the number of same-day phone calls/visits and excluding emergency visits to the hospital. Therefore, we chose to dichotomize the HSU outcome in order to reduce the potential bias, and this may underestimate the number of overall physician visits. In general, these limitations on the reporting of HSU variables may tend to decrease the detectable differences in HSU in the population; therefore, it is unlikely that the burden attributable to asthma was

overestimated. Another limitation of this study was the lack of information regarding the severity of asthma. Some evidence exists that the most severe asthmatics have the highest morbidity and the most HSU; therefore, it is possible that the most severe asthmatics account for most of the increased HSU.[46-49]

Conclusions

This longitudinal population-based study confirms that asthma is significantly associated with higher hospitalization and HSU in the pediatric population, while children in low-income families are susceptible to higher hospitalization and lower HSU. Programs seeking to decrease the economic burden of pediatric hospitalizations need to focus on asthma and low-income populations.

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Disclaimer

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Deprivation and unintentional injury hospitalization in Quebec children

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Abstract

Injuries disproportionately affect children from deprived areas. This study examines the links between the material and social dimensions of deprivation and injury hospitalizations in children aged 14 years or under from 2000 to 2004. Hospitalization data are from the Quebec hospital administrative data system, whereas socio-economic characteristics of individuals were estimated based on the smallest geographic areas for which Canadian census data were disseminated. The Poisson regression model was used to calculate the relative risks of hospitalization for seven categories of unintentional injury. A total of 24 540 injury hospitalizations were examined. Hospitalization in children is associated with both dimensions of deprivation. Injuries to pedestrians and motor vehicle occupants and injuries related to burns and poisonings are clearly associated with both dimensions of deprivation. These inequalities should be considered in the development of preventive measures.

Key words: *Socio-economic factors, inequalities, children, hospitalizations, Quebec, injuries, trauma, unintentional*

Introduction

Unintentional injuries are the leading cause of death and the third most common cause of hospitalization in Quebec children aged 1 to 14 years. Although the majority of children recover from an injury quickly and completely, some are affected by temporary, or even permanent, disabilities that can significantly restrict their quality of life.[1]

It is generally accepted that some children, particularly those from deprived areas, are at greater risk of sustaining an injury than others.[2] With respect to mortality, the association between socio-economic factors and risk of injury has been extensively measured and illustrated.[3-8] Some claim that inequalities in mortality are increasing,[9] while others claim that gaps have held constant despite the observed decline in mortality rates.[10]

Research on the links between non-fatal injuries and socio-economic factors has yielded mixed results.[11] A number of studies carried out in Quebec in the early 1990s show links between the deprived situation of some populations in the Montreal area and risk of injury in pedestrians and cyclists aged 14 years or under.[5,12-14,16] The relationship between socio-economic characteristics and the risk of childhood injury has also been observed elsewhere in Canada.[4,17,18] Some have observed that unintentional injury hospitalizations among children increased significantly with deprivation,[19-28] while others did not find any association between the two phenomena.[29-31]

Cubbin and Smith (2002) have identified some reasons that may explain these fluctuating results.[11] First, the analyses do not always account for the level of injury severity nor define this level using a threshold that reflects the use of health care services. In the case of hospitalizations, a number of extrinsic factors on injury severity influence the likelihood of hospitalization, including bed availability, distance between home and hospital, concerns about whether the injury was intentional or even patient prefences.[11,33] These factors can affect case identification in different ways. There is a risk of obscuring or magnifying the relationship between the injuries and deprivation if the severity of injuries is considered solely from the standpoint of services use. Second, the injury mechanism (i.e. falls, pedestrians, poisoning, etc.) is not always examined in detail.[17,18] Some authors have nevertheless demonstrated that the effect of socio-economic factors can go in opposite directions when each mechanism is studied independently.[34] Last, Cubbin and Smith (2002) emphasize that there are many measures, sometimes inadequately defined, by which socio-economic status can be expressed, whereas the choice of indicator is generally not justified by the investigators.[11]

Finally, we emphasize that few studies have focused on the social dimension of deprivation, i.e. the effect of social cohesion or isolation on injury risk, although this dimension is equally identified as a health determinant.[35] Recently, a measure of social fragmentation introduced to explain the association between injuries

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and deprivation in Sweden yielded no significant findings, after adjustment, for economic deprivation.[36]

Study objective

This study examines the links between unintentional injuries and deprivation in Quebec children. More specifically, we intend to establish whether hospital morbidity due to unintentional injury is associated with the material and social dimensions of deprivation in children aged 14 years or under in Quebec. We will then verify whether this relationship varies with the most important circumstances surrounding the injury. Finally, we will attempt to note whether the association also applies to severe injuries to ensure that the observed associations are not the result of administrative variations or a different use of health care services.

Methods

Data sources

Data used for this study are drawn from the records of the Quebec hospital client information system, called MED-ÉCHO. All Quebec children aged 14 years or under were selected if they were admitted to hospitals providing general and specialty care from January 1, 2000, to December 31, 2004, for short-term physical care of unintentional injuries. Case identification was based on the external cause of trauma and coded according to the rules of the International Classification of Diseases, Ninth Revision (E800–E949). Hospitalizations due to medical or surgical complications (E870–E879), adverse effects from the therapeutic use of medications (E930–E949) and after effects of injury (E905–E909) were excluded (i.e. 2358 cases). In addition, readmissions and transfers were excluded to limit the effects of variations related to service use and obtain a more robust morbidity indicator.[32] Based on these criteria, we identified 24 540 unintentional trauma-related events resulting in the hospitalization of children 14 years or under in Quebec during the period in question.

TABLE 1
Classification of unintentional injuries and main categories of external causes

Unintentional injuries	E800–E949
Motor vehicle occupants	E810–E819; .0, .1 and .9
Bicyclists	E810–E819; .6 and E826.1
Pedestrians	E810–E819; .7
Poisonings	E850–E869
Falls	E880–E888
Fires and burns	E890–E899 and E924

Our measure of severity is based on the definition of the eligibility criteria used by the Registre des traumatismes du Québec (RTQ) [Québec Trauma Registry], which gathers information on victims of severe injuries. To be identified as severe, cases had to meet one of the following criteria: hospitalization for three days or more, admission to the intensive care unit (ICU), or death during hospitalization. This definition of a severe case was met by 24.8% of the 24 540 cases.

The deprivation index

The administrative health databases in Quebec do not contain socio-economic information. For this reason, we used the deprivation index developed by Pampalon and Raymond (2000), which estimates an individual's socio-economic status using an ecological approach, i.e. by attributing to each individual admitted to hospital the socio-economic level of his or her neighbourhood. The index reflects relative disadvantage in relation to total population, which is expressed through a material and a social dimension. The material dimension reflects available economic resources or poverty, whereas the social dimension expresses the level of social cohesion or isolation, i.e. the quality or fragility of the social network.[35]

The index is obtained through the application of principal component analysis of six indicators taken from Canada's 2001 census, chosen for their known association with health inequalities.[36] The material dimension of the index primarily consists of the following indicators: the proportion of persons with no high school diploma, the employment to population ratio and the average personal income. The social dimension of the index primarily consists of the following indicators: the proportion of persons who are separated, divorced or widowed, the proportion of persons living alone and the proportion of single-parent families. For both dimensions, a value is calculated for each dissemination area (DA), which is defined as a small, relatively stable geographic unit composed of one or more adjacent dissemination blocks, with 400 to 700 inhabitants, for which all census data are disseminated.[35] The values are then grouped into quintiles (i.e. groups of 20%) to create the index, ranging from the most privileged (i.e. quintile 1) to the least privileged (i.e. quintile 5).[36] The key point is that each DA can be linked to a postal code, which appears in all administrative health records in Quebec. This strategy can be used to estimate the level of deprivation of the individuals for whom information is collected in our hospitalization records.

Analysis

Relative risks (RRs) of unintentional injury hospitalization were calculated along with confidence intervals of 95% (CI) by Poisson regression modelling using the GENMOD procedure (i.e. SAS, version 9.1) for each material and social deprivation quintile. The RRs were adjusted for differences in age, sex and residence location[i] between quintiles, but also for the presence of the other dimension of the index. For each analysis, the RR is interpreted based on the reference category, i.e. the most

i Census Metropolitan Area (CMA) of Montreal, other CMAs, other census agglomerations, small towns and rural areas.

privileged quintile, for which the RR is set at 1.00. The value associated with the other quintiles expresses the RR of hospitalization between the most privileged quintile and the other quintiles.

Results

From 2000 to 2004, the annual average number of unintentional injuries resulting in hospitalization in children aged 0 to 14 in Quebec was 4908 (Table 2). This amounts to an annual rate of 384 injury hospitalizations per 100 000 children. This rate is substantially higher in boys than in girls (i.e. 480 per 100 000 and 285 per 100 000, respectively). It peaks in children aged 0 to 4 years (i.e. 421 per 100 000), declines in children aged 5 to 9 years (i.e. 336 per 100 000) and then rises again in children aged 10 to 14 years (i.e. 403 per 100 000).

An examination of hospitalizations from a socio-economic standpoint indicates that they appear to be strongly associated with the material dimension of the deprivation index, with the rate increasing from 357 hospitalizations per 100 000 in children in the most privileged quintile (i.e. Q1) to 426 in those from deprived areas (i.e. Q5). The association with the social dimension of deprivation is less pronounced. Children in the most privileged category have a slightly lower hospitalization rate than children in the least privileged category (i.e. 367 vs. 401 per 100 000).

Injury mechanisms and location

There are varying degrees of differences in most injury mechanisms between socio-economic groups, which are generally

TABLE 2

Annual average numbers and injury hospitalization rates by age, sex, area of residence and the two dimensions of the deprivation index in children aged 14 years or under, based on severity, for all of Quebec, 2000 to 2004

	Injuries resulting in hospitalization			
	All		Severe	
	Number	Rate*	Number	Rate*
Age				
0 to 4 years	1561	420.6	365	98.2
5 to 9 years	1519	335.6	342	75.5
10 to 14 years	1829	403.1	511	112.6
Sex				
Boys	3127	480.4	811	124.5
Girls	1781	284.5	406	64.9
Area				
Small towns and rural areas (< 10 000 inhabitants)	1304	446.0	368	121.3
Census agglomerations (10 000 to 100 000 inhabitants)	720	494.1	153	101.7
Other metropolitan areas (>100 000 inhabitants)	905	394.1	196	87.1
Census Metropolitan Area of Montreal	1978	327.4	500	83.7
Material deprivation				
Q1-Privileged quintile	841	356.6	182	78.8
Q2	907	356.0	213	85.6
Q3	975	380.7	230	90.6
Q4	1032	397.3	267	101.4
Q5-Deprived quintile	1152	426.0	325	116.2
Social deprivation				
Q1-Privileged quintile	1092	366.9	254	83.8
Q2	1088	374.1	265	90.5
Q3	1038	390.3	266	100.8
Q4	918	398.4	234	102.9
Q5-Deprived quintile	773	401.3	197	104.2
Total	**4908**	**384.3**	**1217**	**95.3**

* Rate adjusted for the other dimension of the index, age, sex and area of residence

Sources: INSPQ, MED-ÉCHO hospitalization records, 2000 to 2004
MSSS, demographic outlook based on the 2001 census

more pronounced for the material dimension of the index. The gradients are particularly obvious for pedestrians, motor vehicle occupants, bicyclists, poisonings and fire and burn injuries (Table 3). Transportation-related injury categories are all strongly associated with the material dimension of deprivation, i.e. children from the least privileged areas have significantly higher RRs than their peers from privileged areas (i.e. motor vehicle occupants: RR = 1.69; pedestrians: RR = 3.62; bicyclists: RR = 1.31). RRs for bicyclists are significantly higher when analyses focus exclusively on accidents involving motor vehicles, with children from materially deprived areas still at a disadvantage (i.e. data not shown; RR = 1.75). With respect to the social dimension of the index, children in the most deprived quintile have higher risks of hospitalization due to injuries suffered as a motor vehicle occupant or pedestrian (i.e. RR = 1.32 and 2.36, respectively). This is also found for the categories of poisoning (i.e. material dimension: RR = 1.68; social dimension: RR = 1.66) and fires and burns (i.e. material dimension: RR = 2.05; social dimension: RR = 1.50).

In contrast, the falls category as a whole shows no marked difference based on socio-economic level (i.e. material dimension: RR = 1.01; social dimension: RR = 1.00). Hospitalizations for falls account for more than half (i.e. 51.3%) of all unintentional injury hospitalizations in the study population, with this category covering a wide variety of circumstances. A different picture emerges (Table 4) when the main circumstances surrounding falls are identified. Children from materially deprived areas have a higher RR than their peers in privileged areas for falls on stairs (i.e. RR = 1.36), falls from the top of a building (i.e. RR = 2.39) and, to a lesser extent, falls from one level to another (i.e. RR = 1.09), including falls from a bed or chair (i.e. data not shown; RR = 2.30). A similar trend is observed for the social dimension of the index only for falls from the top of a building (i.e. RR = 1.96). Conversely, the RR for falls on same level from slipping, tripping or stumbling is substantially lower in children from deprived areas.

Moreover, between the injury location and both dimensions of the index, there also exists an association that changes, depending on the characteristics of the location in question[ii] (Table 5). For example, children from deprived areas have a higher RR of home injuries than their peers in privileged areas (i.e. material dimension: RR = 1.50; social dimension: RR = 1.18). Conversely, materially deprived children have a significantly lower RR of recreational or sport-related injuries than children from privileged areas (i.e. RR = 0.66).

Nature of main traumatic injury and severity of injuries sustained

To ensure that the observed associations were not caused by administrative variations or a differential use of health care services, our analyses were considered from the standpoint of injury characteristics. First, we examined the nature of the main traumatic injury by isolating a group of similar mechanisms, i.e. transportation accidents involving a pedestrian, bicyclist or motor vehicle occupant (Table 6). With respect to the material dimension, the RR of a skull fracture and intracranial injury appears to be significantly higher in children from deprived areas compared with children in privileged categories (i.e. material dimension: RR = 1.67; social dimension: RR = 1.52). A similar finding, but of greater severity, emerges for lower limb injuries (i.e. material dimension: RR = 2.58; social dimension: RR = 1.70) in contrast to upper limb fractures. Next, we repeated each analysis carried out to this point by selecting cases of severe injury only (Tables 7 to 9). Overall, the examination of severe injuries indicates that the measured associations persist and are nearly always more pronounced for the material dimension than for the social dimension, for which there is no clear trend.

Discussion

The results of the study show clearly that in Quebec, children from deprived areas are at greater risk of injury hospitalization than children from privileged areas. Recent data have confirmed the relationship between socio-economic characteristics and risk of childhood injury for all of Quebec, as observed in the early 1990s for the Montreal region.[5,12,14,16] Our results suggest that these socio-economic differences exist not only in injury categories related to road accidents, but also, to varying degrees, in other categories such as injuries related to fires and burns, poisonings and certain circumstances surrounding falls, including falls on stairs. Unintentional injury in Quebec children are generally influenced by the two dimensions of deprivation. Most studies have underscored the association between risk of injury and the material dimension of deprivation (i.e. level of education, unemployment, income, father's occupation, access to a vehicle, housing tenure, financial difficulties, etc.),[5,13,18,20,22,28,34,37] whereas the social dimension was viewed only partially through the lens of single-parent families, usually used as an indicator of poverty.[47,58] However, our results suggest that the two dimensions of deprivation are independently associated with risk of hospitalization following an injury and that their effects may be cumulative. These results lend greater insight to the observations made for the entire Quebec population from 1997 to 2000,[53] when no significant trend between economic deprivation and unintentional traumas had previously been observed. Similarly, our results contrast with those recently obtained in the Swedish context, where no significant correlation between social isolation and injuries persisted after adjustment for economic deprivation.[56]

In order to minimize the effects of extrinsic factors on the severity of injuries on the probability of hospitalization, a severity measure was used to limit the analysis of injuries associated with a higher probability of hospitalization. Thus, as Hippisley-Cox et al. (2002) had observed for the Trent

ii Accident location only available for codes E850–E869 and E880–E928.

TABLE 3

Average annual number, adjusted* hospitalization rate and RR† for main categories of unintentional injuries by the two dimensions of the deprivation index in children 14 years or under, for all of Quebec, 2000 to 2004

Trauma categories	Deprivation index							
	Material dimension				Social dimension			
	Number	Rate	RR	95% CI	Number	Rate	RR	95% CI
Unintentional injuries								
Q1-Privileged quintile	841	356.6	1		1092	366.9	1	
Q2	907	356.0	1.00	0.96-1.04	1088	374.1	1.02	0.98-1.06
Q3	975	380.7	1.07	1.02-1.11	1038	390.3	1.06	1.02-1.11
Q4	1032	397.3	1.11	1.07-1.16	918	398.4	1.09	1.04-1.13
Q5-Deprived quintile	1152	426.0	1.19	1.14-1.25	773	401.3	1.09	1.05-1.14
Motor vehicle occupants								
Q1-Privileged quintile	16	8.0	1		32	10.5	1	
Q2	24	10.4	1.30	0.97-1.73	31	10.1	0.96	0.77-1.20
Q3	30	11.5	1.43	1.08-1.89	36	13.1	1.25	1.01-1.55
Q4	36	12.9	1.61	1.22-2.12	25	11.5	1.10	0.87-1.39
Q5-Deprived quintile	42	13.6	1.69	1.28-2.24	23	13.9	1.32	1.03-1.69
Pedestrians								
Q1-Privileged quintile	11	4.2	1		18	6.3	1	
Q2	18	7.0	1.69	1.21-2.38	17	6.4	1.01	0.76-1.36
Q3	21	8.5	2.03	1.46-2.84	22	8.7	1.39	1.05-1.84
Q4	25	9.7	2.34	1.69-3.24	23	9.6	1.53	1.16-2.03
Q5-Deprived quintile	39	15.1	3.62	2.65-4.95	33	14.8	2.36	1.81-3.08
Bicyclists								
Q1-Privileged quintile	63	27.1	1		90	30.5	1	
Q2	72	28.0	1.03	0.89-1.20	86	29.3	0.96	0.84-1.10
Q3	79	30.5	1.13	0.97-1.31	85	32.0	1.05	0.92-1.20
Q4	90	34.7	1.28	1.10-1.49	76	32.7	1.07	0.93-1.23
Q5-Deprived quintile	96	35.4	1.31	1.12-1.52	63	32.7	1.07	0.92-1.25
Poisonings								
Q1-Privileged quintile	34	16.3	1		50	16.7	1	
Q2	43	17.5	1.07	0.88-1.31	57	19.0	1.14	0.96-1.35
Q3	50	18.9	1.16	0.95-1.42	52	19.3	1.15	0.97-1.37
Q4	62	22.8	1.40	1.15-1.70	57	25.0	1.49	1.26-1.78
Q5-Deprived quintile	78	27.4	1.68	1.39-2.04	51	27.9	1.66	1.39-2.00
Falls								
Q1-Privileged quintile	493	200.0	1		578	195.2	1	
Q2	486	186.4	0.93	0.88-0.99	557	194.3	1.00	0.94-1.05
Q3	511	199.9	1.00	0.94-1.06	530	200.2	1.03	0.97-1.08
Q4	502	197.0	0.98	0.93-1.04	469	202.1	1.04	0.98-1.09
Q5-Deprived quintile	528	202.9	1.01	0.96-1.08	384	194.7	1.00	0.94-1.06
Fires and burns								
Q1-Privileged quintile	15	6.1	1		19	6.5	1	
Q2	17	6.6	1.09	0.80-1.50	20	7.1	1.09	0.83-1.45
Q3	20	7.7	1.27	0.93-1.73	24	9.2	1.42	1.08-1.86
Q4	23	8.9	1.46	1.08-1.98	24	10.3	1.59	1.21-2.08
Q5-Deprived quintile	33	12.4	2.05	1.52-2.74	20	9.7	1.50	1.12-2.01
Total	**4908**	**384.3**			**4908**	**384,3**		

* Rate adjusted for the other dimension of the index, age, sex and area of residence

† Relative risk

Sources: MSSS, Med-Écho hospitalization records, 2000 to 2004
MSSS, demographic outlook

TABLE 4

Average annual number, adjusted* hospitalization rate and RR† for the main categories of falls by the two dimensions of the deprivation index in children 14 years or under, for all of Quebec, 2000 to 2004

Circumstances of falls	Deprivation index							
	Material dimension				Social dimension			
	Number	Rate	RR	95% CI	Number	Rate	RR	95% CI
Falls on or from stairs (E880)								
Q1-Privileged quintile	29	11.9	1		44	14.9	1	
Q2	33	13.0	1.09	0.87-1.37	45	15.5	1.05	0.87-1.26
Q3	38	14.8	1.24	0.99-1.55	34	12.7	0.86	0.70-1.05
Q4	37	14.5	1.21	0.97-1.52	32	13.8	0.93	0.76-1.14
Q5-Deprived quintile	44	16.3	1.36	1.08-1.71	26	13.3	0.90	0.72-1.12
Falls from the top of building (E882)								
Q1-Privileged quintile	6	2.6	1		8	2.8	1	
Q2	7	2.8	1.08	0.66-1.76	11	4.0	1.43	0.96-2.14
Q3	11	4.3	1.66	1.06-2.60	8	3.1	1.13	0.73-1.75
Q4	10	3.7	1.42	0.89-2.26	12	5.1	1.84	1.23-2.75
Q5-Deprived quintile	17	6.2	2.39	1.54-3.69	11	5.4	1.96	1.29-2.99
Other falls from one level to another (E884)								
Q1-Privileged quintile	172	68.7	1		202	68.7	1	
Q2	178	68.1	0.99	0.90-1.09	197	69.3	1.01	0.92-1.10
Q3	179	70.4	1.02	0.93-1.13	186	70.8	1.03	0.94-1.13
Q4	184	72.6	1.06	0.96-1.16	171	73.3	1.07	0.97-1.17
Q5-Deprived quintile	192	74.6	1.09	0.98-1.20	148	73.6	1.07	0.97-1.18
Falls on same level from slipping, tripping or stumbling (E885)								
Q1-Privileged quintile	163	64.3	1		162	54.6	1	
Q2	142	53.6	0.83	0.75-0.92	153	53.4	0.98	0.89-1.08
Q3	135	53.0	0.82	0.74-0.92	152	57.1	1.05	0.95-1.16
Q4	134	53.2	0.83	0.74-0.92	123	53.0	0.97	0.87-1.08
Q5-Deprived quintile	116	45.7	0.71	0.63-0.80	100	50.8	0.93	0.83-1.04
Falls on same level from collision, pushing or shoving, by or with another person (E886)								
Q1-Privileged quintile	38	15.3	1		19	17.9	1	
Q2	36	13.7	0.89	0.73-1.10	20	15.9	0.89	0.74-1.06
Q3	47	18.4	1.20	0.98-1.46	24	14.7	0.82	0.68-0.99
Q4	37	14.8	0.96	0.78-1.19	24	15.7	0.87	0.72-1.06
Q5-Deprived quintile	39	15.5	1.01	0.81-1.25	20	12.4	0.69	0.56-0.86
Other falls (E881, E883, E887 and E888)								
Q1-Privileged quintile	85	36.7	1		109	36.3	1	
Q2	89	35.0	0.95	0.83-1.09	106	36.2	1.00	0.88-1.12
Q3	101	39.1	1.06	0.93-1.22	111	41.6	1.15	1.02-1.29
Q4	100	38.2	1.04	0.91-1.19	94	41.2	1.13	1.00-1.29
Q5-Deprived quintile	121	44.1	1.20	1.05-1.38	74	39.3	1.08	0.94-1.24

* Rate adjusted for the other dimension of the index, age, sex and area of residence

† Relative risk

Sources: MSSS, Med-Écho hospitalization records, 2000 to 2004
MSSS, demographic outlook

TABLE 5

Annual average number, adjusted* hospitalization rate and RR† for the place of injury by the two dimensions of the deprivation index in children aged 14 years or under, for all of Quebec, 2000 to 2004

Injury location	Deprivation index							
	Material dimension				Social dimension			
	Number	Rate	RR	95% CI	Number	Rate	RR	95% CI
Home								
Q1-Privileged quintile	308	128.0	1		399	146.8	1	
Q2	344	138.3	1.08	0.91-1.29	409	154.6	1.05	0.89-1.24
Q3	373	154.4	1.21	1.01-1.44	364	145.0	0.99	0.84-1.17
Q4	406	167.4	1.31	1.10-1.56	382	167.9	1.14	0.97-1.35
Q5-Deprived quintile	467	191.6	1.50	1.26-1.79	345	173.9	1.18	1.00-1.41
Recreational or sports area								
Q1-Privileged quintile	140	49.7	1		138	41.6	1	
Q2	118	43.4	0.87	0.68-1.12	127	41.1	0.99	0.78-1.25
Q3	115	42.9	0.86	0.68-1.10	124	45.9	1.10	0.87-1.40
Q4	103	40.6	0.82	0.64-1.05	97	41.4	1.00	0.78-1.26
Q5-Deprived quintile	84	32.6	0.66	0.51-0.85	72	38.5	0.93	0.72-1.19
Public building								
Q1-Privileged quintile	56	21.9	1		60	19.8	1	
Q2	45	16.8	0.77	0.62-0.95	49	17.2	0.87	0.71-1.07
Q3	48	18.5	0.85	0.69-1.05	55	20.5	1.04	0.85-1.26
Q4	46	18.1	0.83	0.67-1.03	45	18.8	0.95	0.77-1.17
Q5-Deprived quintile	49	19.3	0.88	0.71-1.10	36	18.2	0.92	0.73-1.15
Other specified location								
Q1-Privileged quintile	21	9.5	1		28	8.9	1	
Q2	25	10.2	1.08	0.80-1.45	29	9.4	1.06	0.80-1.39
Q3	26	10.2	1.08	0.80-1.45	25	9.2	1.03	0.78-1.37
Q4	21	7.9	0.83	0.61-1.14	20	9.1	1.02	0.76-1.37
Q5-Deprived quintile	31	10.2	1.08	0.79-1.48	21	12.6	1.43	1.06-1.92
Unspecified location								
Q1-Privileged quintile	199	90.0	1		273	91.6	1	
Q2	229	91.2	1.01	0.90-1.14	281	93.2	1.02	0.91-1.13
Q3	243	93.2	1.03	0.92-1.16	275	99.8	1.09	0.98-1.21
Q4	258	97.8	1.09	0.97-1.22	215	96.1	1.05	0.94-1.17
Q5-Deprived quintile	277	100.1	1.11	0.99-1.25	163	93.0	1.02	0.90-1.14

* Rate adjusted for the other dimension of the index, age, sex and area of residence.

† Relative risk

Sources: MSSS, Med-Écho hospitalization records, 2000 to 2004
MSSS, demographic outlook

TABLE 6

Average annual number, adjusted* hospitalization rate and RR† for the main traumatic injury categories by the two dimensions of the deprivation index in children of 14 years or under, for all of Quebec, 2000 to 2004

Traumatic injury categories	Deprivation index							
	Material dimension				Social dimension			
	Number	Rate	RR	95% CI	Number	Rate	RR	95% CI
Skull fractures and head traumas								
Q1-Privileged quintile	26	11.6	1		41	13.9	1	
Q2	31	12.6	1.08	0.86-1.37	39	13.3	0.96	0.79-1.17
Q3	43	16.7	1.44	1.15-1.80	47	17.7	1.27	1.06-1.54
Q4	55	20.8	1.79	1.44-2.22	43	18.4	1.33	1.09-1.61
Q5-Deprived quintile	54	19.4	1.67	1.34-2.09	40	21.1	1.52	1.25-1.87
Upper limb fractures								
Q1-Privileged quintile	28	11.0	1		34	11.4	1	
Q2	30	11.2	1.01	0.80-1.28	33	11.4	1.00	0.80-1.24
Q3	24	9.5	0.86	0.67-1.10	31	11.6	1.02	0.81-1.26
Q4	33	13.0	1.18	0.93-1.49	26	11.2	0.98	0.78-1.24
Q5-Deprived quintile	30	11.9	1.08	0.84-1.38	22	10.8	0.95	0.74-1.22
Lower limb fractures								
Q1-Privileged quintile	10	4.3	1		21	7.0	1	
Q2	17	7.0	1.62	1.15-2.28	16	5.5	0.79	0.59-1.05
Q3	20	7.9	1.83	1.30-2.57	18	7.1	1.02	0.77-1.35
Q4	19	7.3	1.69	1.20-2.40	19	8.2	1.18	0.89-1.56
Q5-Deprived quintile	31	11.2	2.58	1.85-3.60	24	11.8	1.70	1.29-2.24

* Rate adjusted for the other dimension of the index, age, sex and area of residence

† Relative risk

Sources: MSSS, Med-Echo hospitalization records, 2000 to 2004
MSSS, demographic outlook

TABLE 7

Average annual number, adjusted* hospitalization rate and RR† for the main categories of severe unintentional injuries by the two dimensions of the deprivation index in children 14 years or under, for all of Quebec, 2000 to 2004

Trauma categories	Deprivation index							
	Material dimension				Social dimension			
	Number	Rate	RR	95% CI	Number	Rate	RR	95% CI
Unintentional injuries								
Q1-Privileged quintile	182	78.8	1		254	83.8	1	
Q2	213	85.6	1.09	0.99-1.19	265	90.5	1.08	1.00-1.17
Q3	230	90.6	1.15	1.05-1.26	266	100.8	1.20	1.11-1.30
Q4	267	101.4	1.29	1.18-1.41	234	102.9	1.23	1.13-1.33
Q5-Deprived quintile	325	116.2	1.48	1.35-1.61	197	104.2	1.24	1.14-1.36
Motor vehicle occupants								
Q1-Privileged quintile	6	2.9	1		15	4.8	1	
Q2	12	5.0	1.70	1.38-2.68	12	3.7	0.77	0.55-1.09
Q3	11	4.1	1.39	0.87-2.23	18	6.3	1.32	0.96-1.80
Q4	16	5.7	1.94	1.24-3.06	8	3.8	0.79	0.54-1.16
Q5-Deprived quintile	17	5.4	1.85	1.16-2.93	9	5.4	1.13	0.76-1.68
Pedestrians								
Q1-Privileged quintile	5	1.8	1		11	3.7	1	
Q2	8	3.2	1.79	1.08-2.96	8	3.1	0.83	0.55-1.24
Q3	11	4.6	2.52	1.56-4.09	12	5.0	1.34	0.93-1.94
Q4	15	5.9	3.26	2.04-5.21	14	5.7	1.53	1.07-2.21
Q5-Deprived quintile	22	8.5	4.67	2.96-7.38	16	7.0	1.89	1.32-2.72
Bicyclists								
Q1-Privileged quintile	16	6.8	1		24	8.1	1	
Q2	16	6.2	0.91	0.67-1.24	23	8.1	0.99	0.67-1.24
Q3	23	9.1	1.33	0.99-1.78	26	9.8	1.21	0.99-1.78
Q4	23	8.9	1.31	0.97-1.76	19	8.3	1.02	0.97-1.76
Q5-Deprived quintile	30	11.4	1.67	1.24-2.23	16	8.3	1.02	0.76-1.36
Poisonings								
Q1-Privileged quintile	7	2.8	1		7	2.2	1	
Q2	9	3.4	1.18	0.76-1.85	9	3.2	1.47	0.94-2.30
Q3	9	3.4	1.21	0.77-1.91	11	4.4	2.03	1.32-3.12
Q4	13	5.0	1.74	1.14-2.67	11	4.8	2.19	1.42-3.39
Q5-Deprived quintile	16	5.8	2.05	1.35-3.13	14	7.1	3.22	2.10-4.94
Falls								
Q1-Privileged quintile	77	31.5	1		91	30.4	1	
Q2	85	33.0	1.05	0.91-1.20	94	32.9	1.08	0.95-1.23
Q3	83	32.6	1.03	0.90-1.19	92	35.1	1.16	1.01-1.32
Q4	87	33.9	1.07	0.93-1.24	87	37.8	1.25	1.09-1.42
Q5-Deprived quintile	101	38.1	1.21	1.05-1.40	68	34.3	1.13	0.98-1.31
Fires and burns								
Q1-Privileged quintile	10	4.3	1		12	3.9	1	
Q2	10	4.1	0.97	0.66-1.44	14	5.1	1.31	0.93-1.85
Q3	12	4.6	1.09	0.74-1.60	15	5.7	1.49	1.05-2.10
Q4	16	6.2	1.45	1.01-2.08	17	7.4	1.92	1.37-2.69
Q5-Deprived quintile	22	8.2	1.93	1.36-2.76	13	6.3	1.64	1.13-2.37

* Rate adjusted for the other dimension of the index, age, sex and area of residence

† Relative risk

Sources: MSSS, Med-Écho hospitalization records, 2000 to 2004
MSSS, demographic outlook

TABLE 8

Average annual number, adjusted* hospitalization rate and RR† for the main circumstances of falls resulting in severe injuries by the two dimensions of the deprivation index in children 14 years or under, for all of Quebec, 2000 to 2004

Circumstances of falls	Deprivation index							
	Material dimension				Social dimension			
	Number	Rate	RR	95% CI	Number	Rate	RR	95% CI
Falls on or from stairs or steps (E880)								
Q1-Privileged quintile	3	1.2	1		5	1.8	1	
Q2	6	2.4	2.00	1.05-3.78	7	2.4	1.34	0.81-2.21
Q3	6	2.4	1.97	1.03-3.76	5	2.0	1.10	0.64-1.89
Q4	5	1.8	1.47	0.74-2.92	6	2.4	1.35	0.79-2.31
Q5-Deprived quintile	8	3.0	2.51	1.32-4.79	4	2.3	1.25	0.70-2.24
Falls from or out of building or other structure (E882)								
Q1-Privileged quintile	2	0.7	1		3	0.8	1	
Q2	2	0.8	1.04	0.40-2.72	3	0.9	1.13	0.53-2.42
Q3	3	1.4	1.86	0.78-4.40	2	0.6	0.74	0.30-1.79
Q4	2	0.6	0.81	0.29-2.22	3	1.3	1.61	0.76-3.43
Q5-Deprived quintile	5	1.6	2.16	0.92-5.08	3	1.8	2.12	0.98-4.61
Other falls from one level to another (E884)								
Q1-Privileged quintile	21	8.3	1		26	8.6	1	
Q2	27	10.5	1.26	0.98-1.63	28	9.8	1.14	0.90-1.45
Q3	26	10.4	1.25	0.96-1.63	29	11.1	1.29	1.02-1.64
Q4	29	11.4	1.37	1.06-1.78	26	11.4	1.32	1.03-1.69
Q5-Deprived quintile	32	12.0	1.44	1.10-1.87	26	12.9	1.50	1.17-1.93
Falls on same level from tripping, slipping or stumbling (E885)								
Q1-Privileged quintile	31	12.5	1		32	10.9	1	
Q2	32	11.9	0.95	0.76-1.19	30	10.4	0.96	0.77-1.20
Q3	23	8.8	0.70	0.55-0.90	32	12.2	1.13	0.90-1.40
Q4	29	11.6	0.92	0.73-1.17	29	12.7	1.17	0.93-1.46
Q5-Deprived quintile	26	10.2	0.82	0.63-1.05	17	8.5	0.78	0.60-1.02
Falls on same level from collision, pushing or shoving by or with another person (E886)								
Q1-Privileged quintile	9	3.4	1		12	3.0	1	
Q2	7	2.8	0.81	0.52-1.25	14	3.7	1.25	0.84-1.87
Q3	10	3.7	1.09	0.71-1.66	15	2.8	0.94	0.60-1.45
Q4	7	2.8	0.82	0.51-1.30	17	3.3	1.11	0.72-1.71
Q5-Deprived quintile	7	2.9	0.84	0.52-1.36	13	2.7	0.90	0.55-1.47
Other falls (E881, E883, E887 and E888)								
Q1-Privileged quintile	12	5.2	1		16	5.2	1	
Q2	11	4.6	0.89	0.61-1.28	16	5.5	1.06	0.77-1.44
Q3	15	5.9	1.15	0.81-1.63	17	6.4	1.21	0.89-1.65
Q4	15	5.7	1.11	0.78-1.59	15	6.8	1.29	0.94-1.78
Q5-Deprived quintile	23	8.2	1.58	1.12-2.23	12	6.4	1.22	0.86-1.73

* Rate adjusted for the other dimension of the index, age, sex and area of residence

† Relative risk

Sources: MSSS, Med-Écho hospitalization records, 2000 to 2004
MSSS, demographic outlook

TABLE 9

Average annual number, adjusted* hospitalization rate and RR† for the incident location of severe injuries, by the two dimensions of the deprivation index in children 14 years or under, for all of Quebec, 2000 to 2004

Incident location	Deprivation Index							
	Material dimension				Social dimension			
	Number	Rate	RR	95% CI	Number	Rate	RR	95% CI
Home								
Q1-Privileged quintile	80	32.5	1		96	32.4	1	
Q2	91	36.5	1.12	0.92-1.38	109	40.3	1.24	1.03-1.50
Q3	91	36.7	1.13	0.92-1.38	95	38.2	1.18	0.97-1.43
Q4	112	45.9	1.41	1.15-1.73	106	45.4	1.40	1.16-1.69
Q5-Deprived quintile	125	48.1	1.48	1.21-1.82	94	47.0	1.45	1.19-1.77
Recreational or sports area								
Q1-Privileged quintile	27	9.9	1		24	7.2	1	
Q2	25	9.5	0.97	0.67-1.39	25	8.5	1.18	0.82-1.69
Q3	19	7.2	0.73	0.50-1.06	23	8.2	1.14	0.79-1.64
Q4	18	6.8	0.69	0.47-1.02	20	8.6	1.18	0.82-1.72
Q5-Deprived quintile	18	6.8	0.69	0.46-1.04	15	7.7	1.07	0.71-1.61
Public building								
Q1-Privileged quintile	6	2.7	1		8	2.8	1	
Q2	8	3.3	1.22	0.75-1.97	8	2.7	0.96	0.61-1.51
Q3	8	3.0	1.12	0.68-1.85	9	3.2	1.17	0.75-1.82
Q4	7	2.7	1.01	0.60-1.69	8	3.5	1.25	0.80-1.97
Q5-Deprived quintile	8	2.8	1.03	0.61-1.74	4	2.4	0.87	0.50-1.49
Other specified location								
Q1-Privileged quintile	6	5.5	1		8	3.9	1	
Q2	6	4.1	0.74	0.52-1.07	11	4.5	1.17	0.84-1.62
Q3	8	4.2	0.76	0.53-1.10	7	3.9	1.01	0.74-1.37
Q4	7	3.7	0.68	0.47-0.99	7	4.6	1.18	0.84-1.66
Q5-Deprived quintile	11	4.8	0.88	0.61-1.26	5	5.8	1.48	1.04-2.12
Unspecified location								
Q1-Privileged quintile	26	13.1	1		45	14.2	1	
Q2	35	14.5	1.11	0.87-1.42	48	15.7	1.11	0.90-1.37
Q3	45	17.2	1.32	1.04-1.67	54	20.0	1.41	1.15-1.73
Q4	49	18.1	1.38	1.09-1.76	38	17.2	1.21	0.98-1.51
Q5-Deprived quintile	63	20.7	1.58	1.24-2.01	32	19.8	1.39	1.11-1.76

* Rate adjusted for the other dimension of the index, age, sex and area of residence

† Relative risk

Sources: MSSS, Med-Écho hospitalization records, 2000 to 2004
MSSS, demographic outlook

Region in the United Kingdom, associations persist upon examination of severe injuries even when injury mechanisms are studied independently.[22] These findings, however, should be interpreted with caution, given the weak frequency upon which they are based. Moreover, the nature of the injuries sustained also appears to be associated with socio-economic disparities, skull fractures and traumas, and lower limb fractures occurring proportionally more often in children from deprived areas. These results are particularly significant, as they suggest that severe injury hospitalizations (i.e. skull fractures, intracranial injuries and lower limb fractures) are strongly associated with deprivation, whereas no association was found for somewhat less severe injuries (i.e. upper limb fractures) involving mechanisms known for their strong association with deprivation.

Whereas there are numerous associations between socio-economic characteristics and injury risk, how the causal link operates has not been clearly demonstrated. These associations could be attributable to multiple individual or environmental factors that directly or indirectly influence injury risk.[41] A significant amount of the research conducted to date has concentrated on individual characteristics to explain the differences observed in the risk of young children sustaining an injury, including family characteristics such as early motherhood,[26,42,43] single-parent families,[3,38] or even the number of children in the household.[14] Other authors have also pointed to the effect of parents with a low level of education.[8,14] These factors, usually associated with poverty, would particularly influence the immediate level and nature of child supervision. Pless et al. (1989) emphasize that the links between child behavioural characteristics and injury risk in pedestrians and bicyclists were more tenuous than the links between family or neighbourhood characteristics and such injuries. It is obvious here that children from socially isolated environments are at greater risk of hospitalization following an injury, perhaps in part, because the quality of the social network affects the parent's mental health,[52] a risk factor in child injuries. Still another possibility is that, in a single-parent situation, the parent assumes several responsibilities alone, which may limit the nature of supervision provided to the child.[54]

Other approaches have shed new light on the contribution of environmental factors, including the home environment, which can directly or indirectly affect children. With respect to road injuries, for example, a number of authors have suggested that children from deprived areas live in neighbourhoods that have particular characteristics. The arrangement of roads and buildings can influence risk exposure due to the volume and speed of motor vehicle traffic, on-street parking and the lack of safe play areas, causing children to use the roads for "recreation".[24,41,44] In addition, children from deprived areas are more likely to walk to school compared with their peers in privileged areas, and be accompanied by an adult less often.[45,46] It is difficult to separate the variations attributable to individual or environmental characteristics. However, recent observations through multilevel analysis have demonstrated an effect on injury risk independent of home environment—regardless of the effects of individuals' socio-economic characteristics.[26,37,47]

With regard to the other mechanisms, other home environment characteristics have been identified as influencing the risk of injury. Housing conditions can affect injury risk[48] in that poor housing is less likely to meet existing safety standards, especially for electrical and heating systems and stairs. Overcrowded, dilapidated housing generally tends to be occupied by materially deprived families. Moreover, it appears that safe practices and the ownership of safe equipment is less common in families from deprived areas than in those from privileged areas.[49] From this viewpoint, studies carried out in the United Kingdom suggest that hospitalizations for poisoning, particularly from the use of benzodiazepine, antidepressants, and cough and cold medications, were significantly higher in children from deprived areas.[50] The authors explain that the association is due to a greater exposure to these substances in deprived areas, owing to the quantity and availability of potentially toxic products, the locations where they are stored and the containers used to store them. Finally, poverty plays an important role in the lack of ownership of safe equipment and the adoption of safe practices.[49] In other words, the observed differences could be bridged more easily by eliminating economic barriers and distributing safe, affordable or free equipment, for example.

Limitations of this study

The data forming the basis of our study include all hospitalizations in Quebec. However, this knowledge base does not include a known, standardized indicator that would establish a severity level of injuries sustained. Consequently, we used an approximate measure based on the eligibility criteria used by the RTQ database. This could give rise to criticism that the measure's capacity to eliminate administrative variations has not been proven. Furthermore, the MED-ECHO database contains no socio-economic information. To circumvent this problem, we used the deprivation index developed by Pampalon and Raymond (2000). However, an ecological index opens the door to similar errors, i.e. the socio-economic characteristics measured for a DA do not correspond to those of the families within the area. Given the number of studies in which this relationship has been observed through individual and ecological data, we believe that this limitation is of little relevance in this case.

Conclusion

The results of this study suggest that deprivation in Quebec children is associated with hospitalization risks for a great range of unintentional injuries for both dimensions of deprivation. In addition, examination of the injuries sustained tells us that the associations noted are not the result of differential health care services use or even administrative variations, given severe injuries are equally related to deprivation. These findings should be taken into account when developing preventive strategies.

The use of socio-demographic characteristics to identify children at risk of injury in order to develop targeted interventions has recently come under criticism. These

critics have instead recommended using a population-based approach adapted to each population sub-group,[43] because restricting preventive interventions to children from deprived areas means a significant number of injury victims would not benefit from the interventions. On the other hand, it appears that a physical modification of the environment is more successful in preventing injuries than most educational programs.[50] From this perspective, measures aimed at modifying infrastructure to reduce traffic, while taking into account socio-economic inequalities related to injuries in young pedestrians, have produced positive results in injury rates, in absolute terms, and in reducing relative inequalities.[51]

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Injury data in British Columbia: policy maker perspectives on knowledge transfer

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Abstract

Provincial and regional decision makers in the injury prevention field were interviewed in British Columbia (B.C.) to obtain their views about best processes for the transfer or dissemination of relevant data. These decision makers (n = 13) indicated that data should provide them with a holistic and comprehensive picture to support their decision processes. In addition, they felt information about injury types and rates should be linked backward to determinants or causes and forward to consequences or outcomes. This complete chain of data is needed for planning and evaluating health promotion interventions. It was also felt that data providers needed to devote more effort to fostering effective receptor capacity, so that injury prevention professionals will be better able to understand, interpret and apply the data. These findings can likely be generalized to other jurisdictions and policy areas, and offer additional insight into the practicalities of knowledge transfer and exchange in researcher/decision maker partnerships.

Keywords: *burden of injury, knowledge transfer, knowledge utilization, policy, injury prevention*

Introduction

Much effort can and has been invested in generating data about the impact and burden of chronic diseases in Canada, but do we know how best to utilize these data in policy and practice? Knowledge transfer[i] (KT) refers to a process whereby information is made available to decision makers through interactive engagement. Over the past decade, researchers and policy makers have described what inhibits or encourages KT.[1-5] Based on these findings, guidance about mechanisms or strategies for effective implementation of KT has been published.[6,7] Common recommendations include establishing ongoing collaborative relationships between the researcher and decision maker;[6,8,9] fostering appropriate attitudes, values, culture and capacity within health care organizations;[3] and offering clear and timely communication in a shared language appropriate to the target audience.[2,6,10] However, it remains important to pursue a more substantial evidence base around KT practices to ensure research and data-collection efforts are directed appropriately. Empirical case studies with actual datasets in particular contexts, such as the one reported in this paper, should advance our understanding and may offer potential for immediate improvements to practice. While the findings here relate most directly to those interested in injury prevention and health promotion, the issues generated from this study should also be applicable to KT for chronic diseases as well as in health care contexts.

Methods

Data collection involved semi-structured interviews with 13 key decision makers with direct knowledge of injury prevention policy in B.C. The interview schedule is appended. The following organizations were represented in the sample: the B.C. Ministry of Health (recently divided into the Ministry of Health Services and a separate new Ministry of Healthy Living and Sport), the Provincial Health Services Authority (PHSA) and two of the five regional health authorities (RHAs). Interviewees were primarily senior to middle managers, with job titles such as Executive Director, Director, Manager or Project Lead. These individuals would typically be responsible for broad planning, priority setting and/or evaluation functions. The interviews were conducted in June and July 2005.

The interviewer provided each informant with sample data to look over (see Tables 1 and 2, and Figure 1, as examples). Informants were then asked general questions about what sources of data they currently accessed and to provide feedback about the sample data sets. Each interview was audio recorded (with permission) and transcribed. Analysis proceeded using the constant comparison method, i.e. themes and sub-themes were developed

i For details see: http://www.researchtopolicy.ca/whatwehavelearned/develop_approach.asp. Related terms include knowledge translation, knowledge exchange, knowledge utilization, and research dissemination.

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inductively.[11] Written notes prepared by the interviewer provided an additional source of data. Ethics approval was granted by the University of British Columbia Behavioural Research Ethics Board.

The policy environment for injury prevention in B.C.

The five RHAs have been given the responsibility to develop and implement plans and programs for injury prevention. They must determine how much of a priority to give to injury prevention compared to other possible initiatives, assess the suitability and effectiveness of program options, engage other sectors where appropriate and evaluate the success and relative costs and benefits of their efforts. The RHAs are at varying stages of development in injury prevention policy. The PHSA provides support with data gathering, analysis and knowledge translation activities and is an important source of data on patient safety, particularly with respect to adverse drug events, nosocomial infections and radiation-related injury.

The role of the B.C. provincial government is primarily one of stewardship. The province also leads surveillance and monitoring efforts. The Health Authority Division of the Ministry of Health Services negotiates performance agreements with the RHAs. These presently include benchmarks for falls and, generally speaking, are meant to hold the RHAs to public account for their outcomes, based on the resources allocated to them. The Healthy Children, Women and Seniors Branch (recently transferred to help create the new Ministry of Healthy Living and Sport) is the primary policy making and advisory centre for the provincial government on injury matters, along with recommendations from the Provincial Health Officer.

The Provincial Health Officer, who now has functions in both the Ministry of Health Services and the new Ministry of Healthy Living and Sport, has provided assistance to RHAs in setting their benchmarks related to falls and has produced a special report on falls among the elderly that: 1) outlines the magnitude of this issue; 2) measures the impact on the health care system; and 3) provides recommendations for evidence-based prevention strategies.[12] Each RHA must apply these in its own context, of course. Further research and data-collection efforts, in support of developing policy recommendations, have been undertaken since 1997 by the British Columbia Injury Research and Prevention Unit (BCIRPU), located at the Children's and Women's Health Centre of British Columbia. These roles were outsourced following the dismantling of the Ministry's own internal Office of Injury Prevention in 2001. The BCIRPU is expanding its data sources by developing agreements with the Workers' Compensation Board (i.e. WorkSafeBC), Statistics Canada, the Canadian Institute for Health Information (CIHI), the Insurance Corporation of British Columbia (ICBC), the RCMP and BC Ambulance Services.

Other key stakeholders (e.g. Red Cross, RCMP) are involved through such mechanisms as the BC Injury Prevention Leadership Network, a provincial steering committee meant to provide guidance and advice on broad policy directions. Still other entities, such as the BC Aboriginal Health Network, the BC Sport & Recreation Injury Free Advisory Committee and the BC Falls Prevention Coalition, also exist. The BC Healthy Living Alliance, a consortium of primarily chronic disease organizations also plays a supporting role in issues related to healthy living, including injury prevention. The province, PHSA and RHAs are aware of the interest of these groups, but are not always fully aware of their role or how they might link to other stakeholders. In short, the policy environment pertaining to injury prevention in B.C. is somewhat fragmented, consisting of multiple departments, agencies and organizations.

Injury data used in the research

Within this policy environment, researchers at the University of British Columbia have been working on a set of statistical methods to further delineate injury data in this province. This case study is part of an ongoing research program, entitled *Burden of Injury in BC and Its Local Communities: Information and Evidence for Community-based Prevention Strategy, Health Policy and Service Provision* (short-titled *Burden of Injury in BC*), currently funded by the Canadian Institutes of Health Research. The main objectives of the *Burden of Injury in BC* project are: 1) to develop a synthesis of analytic methods for a systematic burden-of-injury research framework that encompasses space-time surveillance monitoring, burden assessment, risk assessment, research dissemination and knowledge translation; and 2) to apply these methods to examine burden-of-injury mortality and disability in B.C. and its local communities.[13,14]

During the policy maker interviews, informants were presented with sample tables of burden-of-injury profiles for each of the five RHAs and for B.C. as a whole. This included mortality and hospitalization counts and rates for major causes of injuries, stratified by gender and based on 1991 to 2000 population-based administrative data.[14,15] Tables 1 and 2 present the corresponding cause-specific statistics on burden-of-injury, measured by years of life lost to premature death (YLLs), years of life lived with disability (YLDs), and disability adjusted life years (DALYs).[15] These burden-of-injury measures were derived based on observed injury mortality and hospitalization counts for the five health authorities and for B.C. as a whole for the calendar years of 1991-2000.[14] The YLL, YLD and DALY estimates in Tables 1 and 2 were derived using disability weight and duration estimates from the 1990 Global Burden of Disease study, specified with zero age weighting and an annual 3% discount rate.[14,15] Note that the DALYs are "health gap" measures that allow the combined impact of mortality and morbidity to be incorporated and assessed simultaneously. The DALY measures were developed under the Global Burden of Disease project,[15] as population health indicators for public health assessment and as a "currency" for cost-effectiveness analysis with respect to priority setting and evaluation of health interventions.[14,15]

Informants were also asked to view two sample maps that depicted annual iatrogenic injury risk estimates for children and youth aged 1 to 19 years for 16 geographic subdivisions of the health authorities, i.e. health service delivery

areas (HSDAs). One of the maps, presented in Figure 1, highlights the HSDAs with high/low iatrogenic injury risks for the male population. Bayesian estimates of annual relative risks, quantified by the ratios of HSDA rates over a B.C. average were derived in order to prepare this map.[13,16] An HSDA was identified as having a high (or low) iatrogenic injury risk if the 95% interval estimates (i.e. the upper and lower limits) of the relative risk were above (or below) one.[13,16]

Results

Findings from the interviews relate to both the content and the processes that should lead to effective dissemination and uptake of injury data by researchers and decision makers in B.C. The content of data sets needs to provide a rounded perspective that addresses both injury causes and consequences. Dissemination processes should be targeted to specific audiences and recognize that individuals and organizations may have differing degrees of capacity to use information.

Data content

The interviewees were familiar with and have used DALY measures for health planning purposes, though one suggests that "[we] probably don't use them as much as we should, but we definitely use them" [#3]. However, they suspect that other audiences are less familiar with this measure and would be better versed with indicators like morbidity and hospitalization rates. One interviewee suggested that DALYs might not have as much traction as other measures, because they are not linked or aligned to the "strategic goals of the health system" [#1]. Health system managers in B.C. are not held accountable by their performance agreements with the province for changes in this measure as they are for some other targets. This suggests, as do findings reported below, that institutional or systemic barriers are important influences on the KT process.

These decision makers wanted rich data so that they could view policy issues in their full complexity. They wanted a data "chain" so that they could look both forward and backward from specific injury events. Currently, much factual and descriptive data are available about injury incidence and prevalence, i.e. what types of injury occur and the demographics of those injured. This is useful, but these policy makers also wanted to know about determinants and contexts of injury, i.e. they sought information to help them understand why circumstances in their own communities are the way they are, and whether there are any unique local concerns, needs or circumstances that ought to be acknowledged and addressed.

Decision makers also wanted to be able to look at data from many possible angles and to consider injury findings in light of a range of variables. Demographics of the people involved, times and locations of incidents, and conditions in the social or physical environment are among the factors that might be relevant in understanding and explaining the local injury picture. This kind of information would likely come from a retrospective investigation and a description of each incident.

> I think what I would like to be able to see is, okay, what are the various types of falls? What are the causes and the impacts and who is most at risk? And so, we need to know first of all, who's falling, when are they likely to fall and what are they doing when they are falling? [#1]

> We know motor vehicle crashes [are] number one, but we need to break it down. What does that actually mean? Is it commercial drivers, is it alcohol, is it due to lack of seatbelt use? [#3]

In addition, determinant and context data are necessary in order for planners to decide how best to intervene to solve the problem and carry out evaluative efforts. The informants had a particular interest in these functions and desired data that would assist them in effective planning and evaluation efforts.

> I think it's a matter of articulating, understanding the issues and the determinants, and how the solutions come in to make a difference, because the solution is obviously predicated on an understanding of the determinants. [#1]

> When I think about data, I'm not thinking about rate of; I'm constantly linking it back to... to evidence for interventions and the data related to that, and linking it back then to my population and the data of my population so that I can develop an appropriate intervention. It's so important to link health data with evidence for effective interventions. [#9]

Policy makers also wanted data about the aftermath of injury. This would require following injury cases over time and gathering information about medium- to long-term consequences at the individual and population levels (including full costing). The "business case" for investing in injury prevention depends upon good knowledge of outcomes.

> The outcome—figuring out, do they recover; do they go back to work; are they able to walk; are they able to resume previous activities or does it precipitate a downward spiral in their health? And, as so often with the elderly, that's what happens. You know, we can talk about ActNow [a provincial government health promotion initiative], we can talk about healthy living and exercise and so forth [but] often, a setback like that for an elderly person is extremely detrimental to their health. [#1]

> For policy decisions, we've really got to turn it [injury data] into a bit of a business case and a business case model [for investment in prevention interventions]. ... We're trying to convince government that this is important to pay attention to, because this burden of illness on the system is really a surrogate for the costs we're spending in the healthcare system. ... So, my advice would be to take this information and convert it into something that the decision makers on the resource allocation ledger can understand, interpret and begin to believe that, if I invest in this other end of the continuum, I'm going to take some pressure off the far end—a very compelling argument. ... For them to know what percentage of spending

> contributes from the overall injuries on sports injuries, drowning and burns, they can then start targeting their response. [#2]

However, according to these informants, the data that would flesh out this data chain are unavailable or difficult to obtain in B.C.

Processes for data dissemination

Several comments directly address dissemination processes. A range of ideas was raised by the interviewees (e.g. using "knowledge brokers") about how the information embedded in indicator data might best be transferred to these decision makers, but all emphasized that the credibility of who transfers the knowledge was important and that the knowledge be tailored to each specific target audience. Those who set priorities, for instance, may need different data about the costs and outcomes of injury than those who are responsible for detailed program evaluation.

> It's really dependent on what you're using it for and who your audience is. From a decision making point of view, if you understand what they say, then it doesn't matter. You can look at raw numbers or raw tables and you can gather the information that you need to make the decision. But it's more in putting a rationale, or putting a business case forward or that kind of stuff where you need to have the whole array of tools. [#5]

The visual depiction of data in map format was seen as having appeal for non-experts (e.g. board or senior-management decision makers). "If you want to disseminate this information widely, to people in policy or practitioners, or whoever you want to digest this information, I think the maps are more effective." [#1] Maps were seen as a quick way to transmit information to audiences that are pressed for time and that are unable or unwilling to read lengthy reports or academic journal articles. In this way, they are comparable to the briefing notes or fact sheets touted by organizations like the Canadian Health Services Research Foundation (www.chsrf.ca) as an effective means of reaching senior decision makers with research-based evidence.

Maps were seen as particularly valuable for presenting comparisons. "You can look at it on the page and compare [yourself with] other people. ... It's nice to see where you are pictorially in relation to the rest of the province." [#7] Interestingly, one respondent from the provincial government framed the issue of comparison in the context of the province's specific intention to encourage competition among the health authorities:

> I like the whole idea of spatial mapping around injuries; I think that's the way we should go ... we're sort of setting up the health authorities to be quite competitive, so we need to be able to map which health authorities have got the highest injury rates and relative risks of certain injuries across the province. [#3]

Maps were identified as a valuable communication tool and a good way to make a point: "If I'm going to be using [data] for the purposes of communication to others, ok, I'll go for the spatial mapping." [#6] Of course, analysis and interpretation are embedded in the argumentative use of data in any form:

TABLE 1
Years of life lost to premature death (YLL), years of life lived with disability (YLD) and disability adjusted life years (DALYs) in British Columbia males, by health authority and cause of injury, 1991-2000 cumulative total

Injury	Males					
	Health authorities					B.C.
	Interior	Fraser	Vancouver coast	Vancouver Island	Northern B.C.	
	Years of life lived with disability (YLD)					
Road traffic injuries	8500	10 096	5489	5951	4656	34 692
Other transport injuries	1691	1424	607	1039	1186	5946
Poisoning	258	372	312	241	175	1357
Falls	3848	5526	3630	3564	2037	18 604
Burns/fires/scalds	1121	1370	1119	982	1033	5624
Drowning	174	336	181	141	120	952
Sports injuries	562	766	467	470	275	2540
Natural and environmental factors	244	180	125	135	155	838
Machinery injuries	4219	4810	1872	2943	2738	16 583
Suffocation and foreign bodies	94	152	97	70	52	464
Other unintentional injuries	8622	9826	5921	7118	6088	37 576
Suicide and self-inflicted injuries	1008	1925	1183	1104	602	5822
Other intentional injuries	1219	2126	1687	1290	1116	7438

TABLE 1 (*continued*)

Years of life lost to premature death (YLL), years of life lived with disability (YLD) and disability adjusted life years (DALYs) in British Columbia males, by health authority and cause of injury, 1991-2000 cumulative total

Injury	Males					
	Health authorities					B.C.
	Interior	Fraser	Vancouver coast	Vancouver Island	Northern B.C.	
Years of life lost to premature death (YLL)						
Road traffic injuries	19 008	19 357	9565	9962	11 081	68 973
Other transport injuries	2781	2794	1904	2350	2914	12 743
Poisoning	5736	17 897	26 815	10 009	3115	63 571
Falls	3295	4284	5125	3702	1042	17 448
Burns/fires/scalds	1112	968	912	720	830	4542
Drowning	2024	2130	1781	1905	1337	9177
Sports injuries	138	78	233	28	64	541
Natural and environmental factors	1269	373	508	374	678	3202
Machinery injuries	1089	845	243	681	897	3755
Suffocation and foreign bodies	871	1433	1248	938	409	4899
Other unintentional injuries	2009	1550	1189	1595	1255	7598
Suicide and self-inflicted injuries	16 335	21 106	19 110	15 252	7861	79 664
Other intentional injuries	2420	4764	4720	2116	2021	16 040
Disability adjusted life years (DALYs)						
Road traffic injuries	27 508	29 452	15 054	15 913	15 737	103 664
Other transport injuries	4473	4218	2510	3389	4099	18 689
Poisoning	5994	18 269	27 127	10 249	3289	64 928
Falls	7143	9810	8755	7266	3079	36 053
Burns/fires/scalds	2233	2338	2031	1701	1863	10 166
Drowning	2197	2466	1962	2046	1457	10 129
Sports injuries	700	844	701	498	339	3082
Natural and environmental factors	1513	553	633	509	833	4040
Machinery injuries	5307	5655	2115	3625	3635	20 338
Suffocation and foreign bodies	965	1585	1344	1008	461	5363
Other unintentional injuries	10 631	11 376	7110	8713	7343	45 173
Suicide and self-inflicted injuries	17 343	23 031	20 293	16 356	8463	85 486
Other intentional injuries	3638	6890	6407	3406	3137	23 478

TABLE 2

Years of life lost to premature death (YLL), years of life lived with disability (YLD) and disability adjusted life years (DALYs) in British Columbia females, by health authority and cause of injury, 1991-2000 cumulative total

Injury	Females					
	Health authorities					B.C.
	Interior	Fraser	Vancouver coast	Vancouver Island	Northern B.C.	
Years of life lived with disability (YLD)						
Road traffic injuries	3971	4501	2495	2690	2222	15 880
Other transport injuries	350	290	149	226	246	1260
Poisoning	136	224	143	141	112	755
Falls	2692	3707	2607	2668	1137	12 811
Burns/fires/scalds	535	771	524	516	373	2720
Drowning	26	34	8	25	7	101
Sports injuries	146	149	108	116	65	584
Natural and environmental factors	179	154	80	109	83	605
Machinery injuries	226	336	183	252	253	1250
Suffocation and foreign bodies	2	3	2	2	1	9
Other unintentional injuries	2646	3341	2214	2333	1833	12 366
Suicide and self-inflicted injuries	816	1579	908	880	555	4738
Other intentional injuries	302	426	331	228	314	1600
Years of life lost to premature death (YLL)						
Road traffic injuries	8242	7846	4857	4423	4098	29 465
Other transport injuries	532	368	467	251	388	2005
Poisoning	2224	4428	8197	3173	1304	19 327
Falls	2841	3108	3411	3441	658	13 458
Burns/fires/scalds	532	776	139	526	454	2428
Drowning	594	422	503	684	168	2372
Sports injuries	27	4	55	23	0	110
Natural and environmental factors	311	150	97	149	185	892
Machinery injuries	106	26	0	10	50	193
Suffocation and foreign bodies	324	600	591	639	35	2188
Other unintentional injuries	271	175	305	193	150	1093
Suicide and self-inflicted injuries	4008	6815	6364	5168	1424	23 780
Other intentional injuries	1873	2260	1878	1425	644	8080
Disability adjusted life years (DALYs)						
Road traffic injuries	12 213	12 348	7352	7113	6320	45 345
Other transport injuries	881	658	616	477	634	3266
Poisoning	2360	4652	8340	3314	1416	20 082
Falls	5533	6814	6018	6109	1795	26 270
Burns/fires/scalds	1068	1547	663	1042	827	5148
Drowning	620	456	512	709	176	2472
Sports injuries	173	154	163	139	65	694
Natural and environmental factors	490	303	178	257	268	1497
Machinery injuries	333	362	183	262	303	1443
Suffocation and foreign bodies	325	603	593	640	36	2197
Other unintentional injuries	2917	3516	2518	2526	1983	13 460
Suicide and self-inflicted injuries	4824	8395	7272	6048	1979	28 518
Other intentional injuries	2174	2686	2209	1653	957	9680

FIGURE 1

High and low iatrogenic injury risk estimates for male British Columbia children and youth aged 1 to 19 years, by health service delivery area, 1991-2000

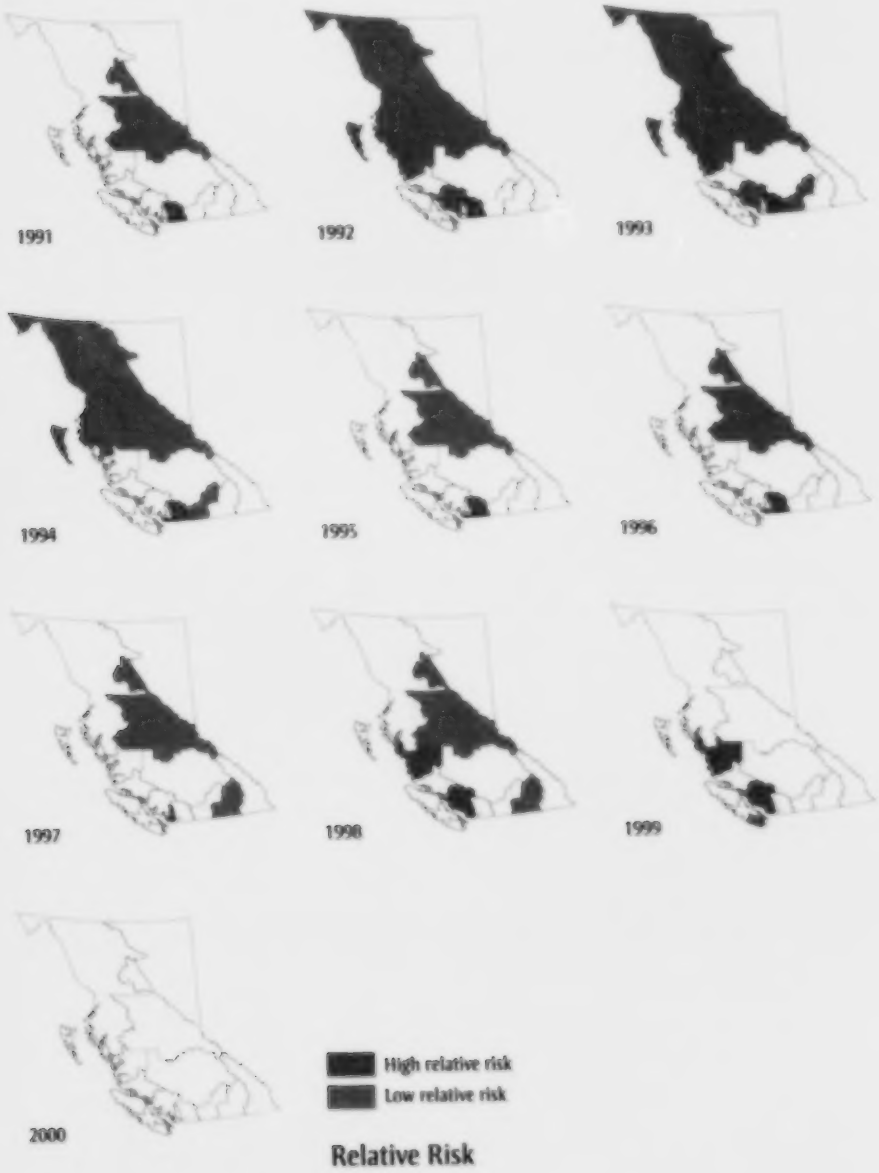
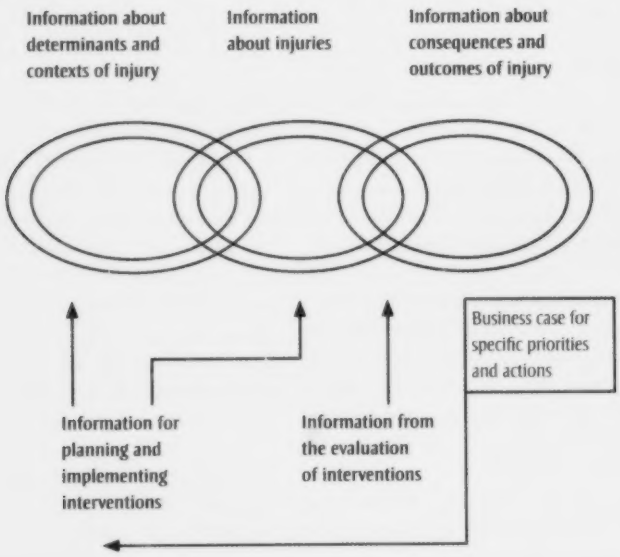


FIGURE 2
The injuries "data chain"


Information about determinants and contexts of injury
Information about injuries
Information about consequences and outcomes of injury
Business case for specific priorities and actions
Information for planning and implementing interventions
Information from the evaluation of interventions

> Something that's spatial like this is really effective if you're trying to make a point. It's data that's [*sic*] being presented in the context of an issue and there's an argument to go along with it and there's, you know, if it's part of a whole package trying to illustrate something, then this kind of spatial representation can be really helpful, because it puts it in context. [#9]

Finally, informants noted that effective uptake of injury data, however presented, depends on the capacity of organizations like the RHAs. This includes both individual knowledge and skills held by data managers, policy analysts and program developers, and the systems needed to allow these individuals to employ their knowledge to affect practice.

Discussion

Effective KT requires that research and data be framed to fit the information needs of decision makers. "Researchers tend to describe the past and present with a focus on the 'what.' Decision makers want and need explanation and prediction. They need to know the 'why' and the 'what if'."[17] Thus, it is perhaps understandable why policy makers in the B.C. injury prevention field stress the importance of knowledge about the determinants of injury and the potential and expected outcomes of RHA interventions.

Based on this research, we suggest the following approach: In order for KT to occur in a given context, researchers should be prepared to collect and present data in multiple formats, reflecting the range of decision makers' needs and capacities. Our respondents in this particular context endorsed the value of visual depictions for senior executive members. Data should also be organized in a way that feeds the stages in the policy development and planning cycle, from agenda setting, policy formulation and decision making to policy implementation and evaluation.[18,19] In particular, priority setting and evaluation are central to the work of health system decision makers. Data sets should be built by researchers in a way that better accommodates and supports these endeavours. Of course, researchers themselves are also limited by time, funding and data availability in what they are able to provide.

Access to the chain of information will allow key stakeholders to follow forward and backward linkages between determinants, situations, interventions and outcomes. This more complex and holistic view runs against the tendency of researchers and other experts to provide extensive and detailed information about a narrow or circumscribed subject. However, such data may be more costly to collect and more complex to interpret, so there are distinct tradeoffs to be made.

To engage decision makers early in the development of research and determination of data needs would be of key importance, as the literature has argued.[4,9,20] Published data reports are more likely to be seen as relevant, understood and, perhaps, utilized when there is early and up-front participation of this nature from decision makers.[21,22]

Finally, these informants made the point quite clearly that information in itself is insufficient to have an impact in the policy context. Information needs to fit into a structure that can accommodate and catalyze it. Much literature to date has focused on the interchange between knowledge producers and users at the individual level.[23] While this is no doubt important, our research also suggests, in line with other recent work on KT, that receptor organizations' systems and structures may determine how well evidence and data can be employed in support of health promotion policy objectives.[24,25]

Our findings are summarized diagrammatically in Figure 2. The injury data that would be valued by these B.C. policy makers make up a chain of information; we have highlighted the interplay between the links in the chain. In our view, this way of looking at KT brings new insight to this field. The nature of decision making is not as linear as this simplified diagram appears, of course. The determinants of injury also likely help shape outcomes or consequences—elderly people who are more prone to injury in certain contexts, such as in long term care facilities, may also have different and less successful outcomes as a result of their age and frailty. Appropriate decisions would also have to account for

and model such inter-relationships. This suggests a need for multi-level analysis, though again, there are trade-offs between this better representation of the real context in which injuries occur (so important for designing appropriate policy interventions) and the greater demands that such complex analyses place on decision makers' information processing abilities. One of the ongoing objectives of the *Burden of Injury in BC* project is to explore and develop KT methods that facilitate effective communication of complex analytic results and uptake of relevant information for policy and priority considerations with respect to injury monitoring, prevention and intervention.

The primary limitation of the current study was the small sample size. It may be that more extensive sampling would have produced other views and further insight into the critical issues around KT and burden-of-injury data. That said, our sampling strategy purposefully included a range of decision makers in different organizations and with different roles and levels of responsibility in injury prevention policy and program development. Convergence of perspectives was observed. However, our informants did not include those identified as data managers, i.e. the persons most likely to handle and interpret detailed data sets on behalf of the RHAs. Further study of the actual practice of injury prevention policy undertaken by RHAs might help indicate how information is actually employed, and whether the detailed data sets asked for here will, in fact, be used or if perhaps decision makers are simply responding to uncertainty or anxiety, or postponing hard choices, by asking for more information.

In looking ahead, further research is required to help elaborate and explain why the data chain that is needed for decision making purposes may be inadequate in the current B.C. policy environment. Is fragmentation the problem or rather the data collection systems? Would progress be advanced through the establishment of a system-wide electronic health record? Working backward from identified needs (as gathered here) to guide systemic reform efforts would be a more grounded approach than current practice, and likely would lead to improved uptake and, ultimately, desired actions at both the individual and system levels.

Conclusion

In this case study we consulted with decision makers around KT approaches related to one particular set of information: injury data. A number of points raised by the respondents are relevant to doing effective KT. We presume that decision makers would have a similar perspective around other policy areas for which they might be mandated to act, and thus believe these insights are transferable beyond injury data. Nonetheless, testing the information found here, e.g. with other chronic diseases, would be useful. In our view, these findings speak to the relevance of the policy environment and the stages in decision makers' policy cycle that must be understood more fully to ensure adequate uptake and utilization of research knowledge.

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Appendix

Interview schedule

1 Please describe your role in relation to injury prevention and control, and/or planning, delivery and policy making pertaining to injury in B.C.

2 Please briefly describe the data and information that you currently access and use in your above-defined role in relation to burden-of-injury in B.C.

3 Are the current data and information that you use adequate?

4 What are the strengths and limitations of the currently available data and information?

5 [Show participant data tables on laptop.] Please refer to the on-screen tables providing detailed information on regional variations in injury-specific mortality, morbidity and burden. [Pause, perhaps 10-15 minutes, to review data.] What are the most relevant data to you in your current role? Why is this the case?

6 Again referring to the data in the tables, what would be the most useful means of presenting this information to you and your colleagues to help ensure that the data are actually used?

7 If these data were made available to you in the manner you have just described, how would you see yourself using this information?

8 Would you see this information contributing directly to priority setting and resource allocation activity in [the Ministry/your organization]? Please describe how.

9 [Show participant geographical analysis on laptop.] Please refer to the information previously depicted in tabular form now presented in a spatial map on the screen. [Pause, perhaps 10-15 minutes, to review map(s).] Is this a useful depiction of these data, or would you prefer the data in tabular form? Why?

10 Noting that we are developing a knowledge-transfer strategy to assess how this information could be disseminated to policy makers, is there anything else that you could tell us to help us in this process?

Thank you very much for participating in this survey.

Complementary therapies for cancer patients: assessing information use and needs

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Abstract

Many cancer patients seek complementary therapies (CTs) for cancer management; however, relatively little is known about patients' CT information seeking behaviour. Therefore, we assessed: 1) cancer patients' use of the types and sources of CT information; 2) their information preferences; and 3) their understanding of the phrase "scientific evidence or proof that a therapy works." We collected data from 404 patients attending the Tom Baker Cancer Centre (TBCC) in Calgary and 303 patients calling the Cancer Information Service (CIS) helpline. In most cases, patients wanted information on the safety of CTs, how CTs work and their potential side effects. Physicians and conventional cancer centres were the most desired sources of CT information, but relatively few patients obtained information via these sources. Although patients were aware of the meaning of scientific evidence, they often used information based on non-scientific evidence, such as patient testimonials. The creation of a supportive care environment in conventional cancer treatment centres, by providing CT information, may help address cancer patients' concerns and alleviate some of the stress that may have been caused by the cancer diagnosis.

Keywords: *CAM, cancer, alternative therapies, complementary therapies, information use and needs, helpline*

Introduction

Complementary therapies (CTs), sometimes referred to as complementary and alternative medicine (CAM), consist of a "group of diverse medical and health care systems, practices and products that are not presently considered part of conventional medicine."[1] Studies assessing the extent of CT use among cancer patients estimate that 7% to 91% of cancer patients report using some form of complementary therapy.[2-8] Although there has been an increase in research to ascertain the safety and effectiveness of CTs, mostly with respect to symptom control,[9,10] the use of CTs still outpaces the evidence.

To date, most research has focused on information needs regarding conventional cancer treatments. A recent, systematic review of cancer patients' information needs and sources[11] identified that patients most frequently seek treatment-related information, such as treatment options and side effects, and that patients tend to consult a wide range of sources, including health care providers, other cancer patients, friends and family members, print material, telephone helplines and the Internet.[12-14] It appears that cancer patients seek sensitive information from telephone helplines and choose Web sites for basic and less sensitive information.[15] Although many patients access the Internet,[16] dependence on Web sites for health information can be problematic, particularly as it relates to CTs. Furthermore, even though the quality of some Web sites is excellent, others lack information regarding the safety or efficacy of CTs,[17] and may report misinformation, or conflicting or inconsistent information.[17-19] Consequently, there is the potential for harm if such advice is followed,[17-19] thus placing users at risk.

Cancer patients seek CT information in part because they are interested in an alternative to conventional medicine.[20] CTs provide patients with a holistic treatment approach and give them a sense of hope[20,21] or control;[22] however, they often become frustrated with the overwhelming amount of CT information and are unsure of what information is credible.[20] Despite the important role that information appears to play in cancer management,[11] relatively little is known about CT information seeking behaviour, such as what information patients consider credible and which information sources they trust. Therefore, we conducted a study to assess: 1) the types and sources of CT information that cancer patients use; 2) the information they prefer; and 3) the meaning of the phrase, "scientific evidence or proof that a therapy works" to them. The results of this study will be of interest to both cancer patients who desire information on CTs and those who treat or provide care to patients interested in CT use.

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Methods

Sampling

Participants were recruited in 2004 from two settings, the TBCC in Calgary, Alberta, Canada; and the Canadian Cancer Society's Canada-wide telephone helpline, the CIS. This sampling approach[23] was chosen to focus on a range of individuals diagnosed with cancer. It allows a comparison of CT use and information seeking between people in two very different contexts. The first was a consecutive sample of new and follow-up adult cancer patients attending the TBCC outpatient clinic who were approached by a research assistant in the clinic waiting areas. The second was a consecutive sample of cancer patients calling the CIS telephone helpline who were recruited by telephone information specialists.

Data collection

Data were collected by means of a pretested, structured questionnaire developed specifically for this study. The questionnaire included basic demographic information, information about the respondent's type of cancer, diagnosis and treatment history, and questions regarding their use of and their search for information about CTs. Most questions had a yes/no, multiple choice or Likert scale response format. Respondents were also encouraged to provide additional comments about CT use for cancer. The questionnaire was pretested in a sample of 20 cancer patients at the TBCC to assess clarity and face-validity of the questions, as well as the recruitment strategy. Interested participants at the TBCC provided consent and completed the questionnaire on-site. Completion of the survey took approximately 10 minutes and most were completed before attending the scheduled clinic appointment. When requested by the participant, assistance was provided in reading and completing the questionnaire. CIS helpline callers who agreed to participate were mailed a questionnaire with a postage-paid return envelope. Follow-up telephone calls were made to those who had not returned the questionnaire within three weeks. A second questionnaire was mailed if the telephone follow-up was unsuccessful.

Data analysis

Descriptive data analysis was performed (i.e. frequency tables, percentages and means) and contingency analyses (i.e. chi-square or t-tests) were used to assess associations between socio-demographic variables, CT use and CT information seeking characteristics using SPSS data analysis software. Respondents' written comments and suggestions were analyzed using descriptive qualitative analysis.[24]

The study was approved by the Conjoint Health Research Ethics Board at the University of Calgary.

Results

Although some demographic and disease characteristics of the two samples (i.e. TBCC and CIS) were different, data on information needs and information seeking were fairly similar. When TBCC and CIS data are significantly different, separate analyses will be presented.

TBCC participants

Four hundred and eighty-four cancer patients in the TBCC Outpatient Clinic were invited to participate in the survey and 404 patients (i.e. 84%) completed it. Most (i.e. 76.6%) survey participants were visiting the TBCC for a follow-up appointment, while others were visiting for a first-time appointment (i.e. 14.1%) or for treatment (i.e. 5.8%). Reasons for not participating included "no time," "too stressed," "anxious" or "overwhelmed."

CIS participants

There were 572 cancer patients who called the CIS telephone helpline that were invited to participate; of these, 394 (i.e. 68.9%) agreed to receive a questionnaire by mail. Of the 388 patients who received the questionnaire, 303 (i.e. 78.0%) returned a completed questionnaire. This included 12 (i.e. 4%) participants who completed the survey during the telephone follow-up. Reasons for not participating were very similar to those provided by TBCC participants, except for "recently diagnosed," which was more common in the CIS sample. Six questionnaires (i.e. 1.5%) were returned with an incorrect mailing address. Overall, the CIS response rate was 54%.

Qualitative analysis

Respondents who voluntarily provided written comments and feedback included 137 from the CIS (i.e. 45.2%) and 24 (i.e. 5.9%) from the TBCC. The majority of the comments expanded on the response choices provided in the survey questions and centred around three areas, i.e. barriers to finding CT information, the need for specific "evidence" and specific CT information needs. Respondents' comments will be used to illustrate the results of the quantitative analysis.

Demographic and disease characteristics

Table 1 shows demographic and disease treatment characteristics of the TBCC and CIS study participants. Gender, age distribution, years since first diagnosis, types of cancer (i.e. breast and genitourinary) and cancer treatment history (i.e. surgery, chemotherapy and hormone therapy) were significantly different between the groups ($p < 0.05$); however, in both the TBCC and CIS samples, the three most common cancers were breast, colorectal and genitourinary (mostly consisting of prostate cancer). The high proportion of females among CIS callers has been previously reported[25] and may explain the higher percentage of respondents with breast cancer in the CIS sample. About 11% of TBCC and CIS respondents (i.e. 11.4% and 10.9%, respectively) reported multiple cancers. This appears rather high; however, in this category, respondents had also included metastases. The data show that CIS participants were diagnosed with cancer more recently than TBCC participants.

CT use

In the questionnaire, CTs were described as "herbs, mental imagery, meditation, yoga, naturopathy, chiropractic and many others. These therapies are different than conventional cancer treatments such as surgery, radiation, chemotherapy and/or hormone therapy and are usually not prescribed by physicians." Table 2 reports data on CT use before and after diagnosis

by each group (i.e. TBCC and CIS). Whereas CT use among CIS patients increased little after the cancer diagnosis, it increased substantially among TBCC patients. In both samples, however, previous CT use appeared to be a strong predictor of CT use after diagnosis (i.e. $p < 0.001$ for both samples). In both samples, females were significantly more likely to use CT than males (i.e. $p = 0.006$ in the TBCC sample and $p = 0.012$ in the CIS sample). Age was only related to CT use in the TBCC group: patients aged 50 or younger were more likely to use CTs than those over age 50 (i.e. $p = 0.008$). Types of CTs were grouped into nine categories and are listed in Table 3. Significant differences in CT use between the two groups were only found for herbs and supplements and special diets. Respondents were asked to check all reasons for using CT treatments that applied to them. Although in a different order, the three most important reasons for CT use in both groups were to improve health, strengthen the immune system, and enhance well-being and quality of life (Table 4). CIS respondents mentioned "to enhance well-being" and "to cure cancer" significantly more than TBCC respondents.

CT information seeking

Among the proportion of the 256 (i.e. 36.8%) respondents who had sought CT information, there was a marginal difference between the two groups, i.e. 35.9% for TBCC respondents and 38.0% for CIS respondents). Table 5 shows the variation in information seeking in the two samples by sex, age and previous CT use. Although the proportion seeking information differed significantly by all three variables in the CIS sample, it was only significantly different for previous CT use in the TBCC sample. Respondents who found the information they needed differed significantly between the two samples ($p = 0.027$). In the TBCC sample, 44.6 % of respondents found *most* of the information they needed compared to 31.5% in the CIS group; 38.8% in the TBCC group versus 55.9% found *some* of the information they needed; and 16.5% in the TBCC group compared to 12.6% in the CIS group did *not* find what they wanted. Of the information seekers who did not find all the information they needed (n = 118), 43.2% indicated that the available information was too general. It was too limited for 39.0%, confusing for 28.8%, overwhelming for 24.4% and contradictory for 23.7%. The only category in which the two groups differed significantly, i.e. 33.3% in the TBCC group and 14.5% in the CIS sample, was the information made false promises. Respondents checked all that applied for this question.

In the written comments, many respondents talked about barriers to finding information. For example, *"Cancer patients can't give up* [looking for information]. *Sometimes doctors wait too long to do treatments; patients need to find other options. It's too bad that many patients don't know about other options (treatments or resources) available to them ... you can't stop."* For those who found information, they also had difficulty trusting the information: *"When you are diagnosed, people literally come out of the woodwork with statements like, 'I know a rural GP or an alternative centre who are regularly curing cancer.' How on earth is a lay person supposed to be able to determine the credibility of such claims?"* Another asked, *"Is there a unified source of credible information available that consults scientists, oncologists, GPs and 'alternative' practitioners and provides intelligent conclusions?"*

As identified in the survey, conflicting information and the sometimes-overwhelming volume of information was a challenge. *"It seems to me one group says one thing and another comes along and says just the opposite. I think I would like some straight answers I could really trust."*

Preferred types of CT information

Respondents were asked what three types of CT information (i.e. out of a list of 8) were most important to them; several respondents identified more than three. Among those who sought information (n = 256), 71.5% considered the most important information to be the safety of the therapy; 67.2%, an explanation of how the therapy works; 62.8%, the potential side effects of the therapy; and 62.4%, proof that the therapy improves well-being. This was followed by cost (48.6%), information from other patients (48.2%), proof that the therapy could cure cancer (39.5%) and time needed to receive the therapy (21.3%). Differences between TBCC and CIS responses were insignificant. In addition, information seekers wanted information that is current (66.9%), explains how the therapy works (63.5%), is easy to understand (58.9%), is scientifically tested (55.8%), is specific (41.5%) and provides a range of information sources (47.1%).

In written comments, respondents expressed interest in CT information on a variety of other topics. One respondent wanted information about a specific cancer type: *"There is so much cancer research, but no one seems to know much about bladder cancer; no support groups, etc. You're on your own. The Centre for Integrated Healing* [a centre in Vancouver, British Columbia that takes a holistic, healing approach to cancer care] *is all the support we get."* Or about preventing recurrence: *"I would be interested in knowing if there is more therapy I should take even though I have been clean for 5 ½ years. ... Is there a way to help re-occurrence* [sic] *through complementary therapy?"* The alleviation of the side effects of conventional treatments interested several respondents: *"If complementary therapies help to alleviate side effects and protect healthy cells and tissues, it would be so beneficial to us undergoing chemo treatment."*

Used versus preferred sources for CT information

Of those who sought CT information, there were marked differences between the people from whom the respondents actually obtained information and their preferred informants (Table 6). Although health professionals such as physicians were often the preferred information source, they were seldom used, and whereas friends or relatives were the most frequently used sources of information, they were not the preferred sources. This was also the case for respondents who were asked where they got the CT information they sought. Even though the Internet, health newsletters and books were used often, the respondents would have preferred to go to conventional cancer centres.

TABLE 1

Demographic and disease characteristics of TBCC and CIS respondents

Characteristic	TBCC n = 404	CIS n = 303	p-value
Female (%)	39.0	77.9	< 0.001
Age range (mean)	18 to 91 (60.0)	25 to 88 (57.3)	0.007
Education (%)			
High school or less	37.6	39.9	0.561
More than high school	62.4	60.1	0.491
Years since diagnosis (range, mean)	< 1 to 23 (3.5)	< 1 to 29 (2.1)	< 0.001
Years (%)	2003 to 2004 71.8	2003 to 2004 38.6	
	2001 to 2002 9.8	2001 to 2002 25.7	
	1999 to 2000 5.8	1999 to 2000 16.7	
	< 1999 12.5	< 1999 18.9	
Types of cancer % (top three)			
Breast	17.1	42.9	< 0.001
Colorectal	7.9	5.9	0.309
Genitourinary	24.5	10.6	< 0.001
Treatment history (%) (previously or currently received)			
Surgery	42.8	61.7	< 0.001
Radiation therapy	38.6	38.0	0.858
Chemotherapy	29.5	44.2	< 0.001
Hormone therapy	21.5	16.2	< 0.001

TABLE 2

Percentage of TBCC and CIS respondents using complementary therapies (CTs)

CT use	TBCC n = 404	CIS n = 303	p-value
Prior to cancer diagnosis	21.5	34.7	< 0.001
Since cancer diagnosis	30.4	36.3	0.101

TABLE 3

Categories of complementary therapies currently used by TBCC and CIS respondents (% of respondents)

CT categories	Examples	TBCC n = 94	CIS n = 103	p-value
Herbs and supplements	Aloe vera, essiac, saw palmetto, flax	44.7	28.2	0.016
Mind-body therapies	Meditation, hypnosis, support groups, relaxation, visualization/imagery	31.9	40.8	0.129
Energy therapies	Acupuncture, homeopathy, Chinese and ayurvedic medicine, exercise, Tai Chi, therapeutic touch, yoga	31.9	28.2	0.678
Vitamins and minerals	Amino acids, iron, vitamins A, B, C	16.0	23.3	0.184
Physical therapies	Chiropractic, massage	14.9	11.7	0.524
Special diets	Naturopathy, juicing diets, Gerson therapy	11.7	22.3	0.045
Extracts and concentrates	Hydrogen peroxide, lycopene, laetrile	7.4	8.7	0.722
Spiritual therapies	Prayer, faith healing and other spiritual rituals	2.1	5.8	0.184

TABLE 4
Reasons for using complementary therapies (% of respondents)

Reasons for CT use	TBCC n = 123	CIS n = 110	*p*-value
To improve health	82.1	74.5	0.160
To enhance well-being and quality of life	65.5	82.7	0.003
To strengthen immune system	73.1	68.2	0.403
To give hope	42.0	45.5	0.539
Because CTs are less toxic/invasive than conventional therapies	40.3	38.2	0.796
To feel in control of cancer treatments	44.5	32.7	0.046
To supplement cancer treatments provided by doctor	33.3	40.9	0.232
To ease side effects of therapy	29.4	39.1	0.148
To cure cancer	23.5	43.6	0.002
To relieve symptoms	25.2	37.3	0.064

TABLE 5
Percentage of TBCC and CIS respondents who had sought CT information by gender, age and previous CT use

Characteristics		TBCC n = 404	CIS n = 303
Gender	Male	32.1	25.4
	Female	41.7	41.1
	p-value	0.052	0.022
Age	≤ 50 years	43.8	51.8
	> 50 years	32.9	31.9
	p-value	0.053	0.001
Previous CT use	Yes	69.4	61.5
	No	26.8	25.1
	p-value	< 0.001	< 0.001

Use of evidence

For the majority of information seekers (i.e. 60.5%), evidence or proof that a complementary therapy works meant that there was scientific research to prove its effectiveness; however, if a scientific report stated that the CT which a respondent was using was ineffective, 47.9% in the TBCC sample and 33.6% in the CIS sample (p = 0.007) would continue to use it. Evidence that a CT works could also mean that the information came from a trusted source (51.6%); the CT worked for others who used it (50.4%); it was "my doctor's recommendation" (27.0%); and "my gut feeling" (17.7%). The two groups differed significantly with respect to "personal experience has proven that it works" (TBCC sample, 47% versus CIS sample, 26.4%).

Some respondents strongly endorsed the need for scientific evidence in their comments. As one person said, *"I would like to see independent bodies such as university studies giving credibility to alternative treatment."* Others expressed concern with the lack of evidence-based information and the possible consequences: *"I have been to a naturopath—not specifically for cancer treatment—but am always sceptical, as there is not much proven about these herbs and maybe they could do more harm than good."* Several respondents were interested in patient testimonials or "softer" evidence, for example, *"I would like to discuss the possibility of using complementary therapy with someone who has had prostate cancer and who used that therapy"* and, *"I hope to read many testimonials on how such treatment has improved the life and health of cancer patients, and even cured them. Surely all these people cannot be biased."* However, others are interested in both types of evidence and take responsibility for their treatment decision, for example, *"Mostly, I want to hear from the scientific community if there are any dangers in using a particular therapy. Then I want to hear from people who have tried it—patients and practitioners. What is their personal experience? Then I'd still weigh the cost to me (i.e. time and money) and make my own decision."*

Communication with physicians about CT use

A large percentage of CT users (i.e. 60.7% in the TBCC group and 67% in the CIS group; p = 0.609) reported having told their doctors about their CT use. Of the combined samples, 30.3% of users did not inform their doctors, and the remaining 6.0% indicated that they would like to tell, but felt they could not do so. Of the CT users who told their doctors (n = 147), 18.2% of users reported that their doctors were very supportive and 43.2% of them had somewhat supportive doctors. Almost nine per cent of respondents (i.e. 8.8%) reported having both doctors who were

TABLE 6
CT information sources identified, used and preferred by TBCC and CIS respondents (% of respondents)

CT information source	TBCC n = 144		CIS n = 112	
	Used	Preferred	Used	Preferred
From whom				
Physician	13.6	76.5	13.4	75.7
Patient/survivor	22.1	50.7	40.2	58.6
Complementary practitioner	32.9	50	36.6	47.7
Pharmacist	9.3	28.7	10.7	35.5
Nurse	10.7	23.5	15.2	20.7
Friend/relative	61.4	17.6	58.9	16.2
Counsellor/psychologist	3.6	6.6	9.8	18
Health food store employee	17.9	5.9	24.1	8.1
From where				
Conventional cancer centres	7.9	57.4	20.2	57.1
Internet	57.9	50.7	57.8	35.7
Health newsletters	40.7	41.9	50.5	38.4
Health organizations	12.9	33.1	28.4	38.4
Books/library	39.3	29.4	52.3	30.4
Scientific journals	14.3	31.6	18.3	24.1
Telephone cancer information services†	41.1	24.1	49.7	
Magazines/newspapers	25	17.6	30.3	13.4
Television	6.4	5.9	12.8	7.1

† "Telephone cancer information services" this response option was included only on the CIS questionnaire

supportive as well as doctors who were not, and 10.8% of users had unsupportive doctors. The remaining 18.9% of CT users did not know whether their doctors were supportive.

In their comments on the questionnaires, several respondents discussed the need for physicians to have more knowledge about CTs and to be willing to discuss CT with patients early in the treatment. As one respondent said, *"It is useless to tell your oncologist about herbal remedies. He has no knowledge of them, nor time to research them, so he also [sic] dismisses them as inconsequential or harmful, with no evidence to support his view."* Another user stated, *"Cancer patients need more information about complementary therapy as soon as they are diagnosed with cancer, and my doctor would be the best person to do this."*

Discussion

For this study, we recruited two consecutive samples of cancer patients from two different populations. The TBCC and CIS samples differed in terms of the percentage of females (which impacts on type of cancer and treatment statistics), time since diagnosis and previous CT use. With a few exceptions, we found that the data are remarkably similar regarding information seeking, and used and preferred information sources, even though we were dealing with a very unique sample of CIS individuals who actively seek cancer-related information and who may be different from other information seekers, in terms of beliefs and attitudes.

The decision to use CTs is highly personal and complex.[22] The reasons participants in the current study stated for using CTs reiterate those reported in the literature.[3,26-28] In most cases, respondents looked to CTs to improve their health, strengthen their immune system or enhance their well-being and quality of life. Physicians, other patients, scientific research or personal intuition may, independently or jointly, influence a patient's decision to use CTs. Information seeking may bring several benefits, such as increased involvement in making treatment decisions, improved ability to cope after diagnosis and treatment, reduced anxiety and mood disturbances, and improved communication with family members.[11] It is therefore important that patients are supported in their search for information and that they have access to accurate, comprehensive information.

Perhaps the most intriguing finding is the difference between used and preferred sources of CT information. In both samples, patients preferred information from conventional health care providers (i.e. physicians, pharmacists and nurses) and conventional cancer centres; however,

TABLE 7
Resource books and Web sites

Books
Ernst E, Pittler MH, Wider B, Boddy K. Oxford handbook of complementary medicine. Oxford: Oxford University Press, 2008. Oncology: p. 342-8. Evidence for all treatments is rated.
Rakel D, Integrative medicine, 2nd ed. Philadelphia: Saunders, and imprint of Elsevier Inc. 2007. Section 13: Integrative oncology – an overview: p. 809-99. Evidence for all treatments is rated.
Ernst E, Pittler MH, Wider B, editors. The desktop guide to complementary and alternative medicine: an evidence-based approach, 2nd ed. Philadelphia: Mosby, an imprint of Elsevier Limited, 2006. Cancer: p. 80-8. Evidence for all treatments is rated.
Kligler B, Lee R. Integrative medicine: principles for practice. New York: McGraw-Hill, 2004. Chapter 23: Integrative approach to oncology: p. 535-49.
Kohatsu W. Complementary and alternative medicine secrets: Q & As about integrating CAM therapies into clinical practice. Philadelphia: Hanley & Belfus, Inc. 2002. Chapter 55: Approach to specific cancers: p. 377-88.
Web sites
The University of Texas MD Anderson Cancer Center Complementary/Integrative Medicine Education Resources: **http://www.mdanderson.org/departments/cimer**
Memorial Sloan Kettering Cancer Center: **http://www.mskcc.org/mskcc/html/44.cfm**
CAMline: **http://www.camline.ca/**
Center for Health and Healing, a service of Beth Israel Medical Center in New York: **http://www.healthandhealingny.org/**
National Center for Complementary and Alternative Medicine (NCCAM): **http://nccam.nih.gov/health/**
Natural Medicines Comprehensive Database – Clinical Management Series: **http://www.naturaldatabase.com/(S(st2arzb2hbi2v355rtipno2p))/nd/ClinicalMngt.aspx?cs=&s=ND**
Natural Medicines Comprehensive Database: **http://www.naturaldatabase.com**
Natural Standard Database: **http://www.naturalstandard.com/**

there was a large gap between preferred and actual sources used. The preference for information from their doctors has been reported in earlier studies,[11] yet relatively few patients asked their doctors for information. This may stem from a reluctance to use valuable resources (e.g. doctor's time) when patients perceive others need these resources more, or they may question a physician's willingness to talk about CTs or his or her knowledge of this subject. Consequently, these patients may find it easier to obtain information from family or friends,[21] the Internet,[14] health newsletters, books and the library. Unfortunately, health information from Web sites often contains conflicting, wrong or incomplete information[18,19] regarding the safety or efficacy of CTs,[17] and family or friends may not have the necessary knowledge to provide evidence-based information.

Given study participants' use of CTs and their preferences for current, scientifically based and easily understood information about this subject, health care providers and conventional cancer centres have an important role to play in disseminating information.[29] It is especially important that health care providers bridge the gap between preferred information sources and those used and open up discussion about this matter with their patients, because so many patients do not report CT use to their physicians.[18] Compared to the literature,[30-31] a fairly large number of participants in this study reported their CT use to their physicians; however, over a third did not. Uncertainty regarding their physician's support of their CT use or, as reported in previous research, a feeling of discomfort in discussing CT use with their conventional health care providers[20] may result in patients seeking opportunities to discuss and gain support for CT use elsewhere.

Since patients may have already collected CT information prior to talking with a health care provider (e.g. obtaining basic information from the Internet),[14] it has been suggested that as cancer information seekers become more skilled at finding information, their needs may shift from seeking information to requiring assistance with interpreting information.[32,33] Although the need for health care providers to be cognizant of available CT information sources has been previously identified,[29,30,32,34] health care providers are also challenged to find valid and comprehensive CT information that they can discuss and share with their patients. Since changing or conflicting information regarding CTs can be confusing for both health care providers and patients seeking information,[35] current, comprehensive information sources would be helpful. CIS telephone helplines may be able to assist health care providers in developing the skills to communicate about CTs, as well as provide them with resources they can use to assist patients in decision making. Information that would be available to both patients and health care providers could include how to choose a complementary practitioner or natural health products. A guide such as "Complementary Healthcare: A Guide for Patients" may be a helpful start.[36] It includes helpful information on where to find CT practitioners and what questions to ask of them. High-quality, evidence-based CT information is increasingly available; Table 7 lists some available resources. Furthermore, the development of the relatively new discipline of integrative oncology reflects a shift in focus from biomedical cancer treatment to the more comprehensive concept of cancer care. Integrative oncology has been defined as "the ability to integrate the best of complementary and mainstream care using a multidisciplinary approach, combining the best of mainstream cancer care and rational, data-based, adjunctive CTs."[37] This development will most likely lead to further development of and guidelines regarding CTs.

The results also showed that patients rely on or trust information sources of non-scientific, research-based evidence. Although the importance of scientific evidence is without question, the literature increasingly points out that non-scientific evidence factors are important to consider as well. Sackett et al. have defined evidence-based

medicine as "the integration of the best research evidence with clinical expertise and patient values."[18] This definition highlights that clinical expertise, partially based on empirical observation, may provide important information above and beyond what can be learned from clinical trials. In addition, it highlights that the patient has important knowledge which is unavailable to the health care provider. Whereas clinical expertise and patient values are limited by their subjective nature, scientific evidence is limited in its bias towards "objectivity," attempt to control and discounting of important subjective factors. Scientific evidence, clinical expertise and patient values combined will greatly contribute to optimal evidence-based patient care.

This study raises important issues regarding patients' need for and use of CT information, despite being limited due to its cross-sectional nature, the general nature of the questions in the questionnaire and two very specific samples that do not allow generalizations to the larger population of CT information seekers. Such information may be helpful for patients, in further clarifying their questions, and for health care providers, in understanding patients' inquiries and learning how to address them.

Conclusion

Cancer patients would prefer to receive CT information from conventional health professionals and cancer centres. They also want this information to be cancer-specific and comprehensive. Cancer information services can play a valuable role in the provision of CT information to both patients and conventional health care professionals. Patients seek information from a number of sources and evaluate the trustworthiness and validity of that information in different, sometimes conflicting, ways. Therefore, it is important to acknowledge that patients may use information based on scientific research as well as "softer" evidence, such as patient testimonials. The creation of a supportive care environment through CT information provision may help address some of the concerns of cancer patients and alleviate some of the stress that may have been caused by the cancer diagnosis.

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The national lung health framework: an opportunity for gender analysis

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Abstract

Smoking related respiratory diseases in Canada represent a huge social and economic burden for both women and men. This article addresses the potential impact of the National Lung Health Framework for reducing disparities between women and men in respiratory health and between sub-populations of women and men. A preliminary analysis of the existing framework documents indicates that sex and gender factors, differences and influences have not yet been clearly or sufficiently identified. Yet, there are sex and gender issues related to tobacco prevention and cessation, lung health and lung disease. In particular, we consider the specific respiratory health needs and experiences of women to demonstrate the need for sex and gender-based analysis within the framework. For example, while there is inconsistent evidence regarding quit rates, women and men have different cessation patterns and reasons for smoking. Although creating a Canada-specific approach to lung health is an important initiative, the sex and gender issues associated with respiratory disease and health need to be explicitly addressed in the planning and development stages of the framework in order to have a beneficial and lasting impact on both women and men.

Key words: *smoking, respiratory diseases, National Lung Health Framework, NLHF, chronic obstructive pulmonary disease, COPD, sex, gender, women*

Introduction

Respiratory diseases in Canada represent a huge social and economic burden. Lung cancer, chronic obstructive pulmonary disease (COPD) and pneumonia, the three leading respiratory causes of death in Canada, were responsible for 15.6% of deaths in men and 13.5% of deaths in women in 2004.[1] The current planning and development of a National Lung Health Framework (NLHF) is an integral step to improving the respiratory health of Canadians. This framework emerged in March 2006 from a workshop entitled "Breathing Matters," which united stakeholders in the mandate to develop a national action plan to improve respiratory health in Canada. Under the auspices of the Canadian Lung Association, the process is being led by an interim steering committee that has coordinated subsequent workshops to guide the framework-development process.[2] Released in August 2008, the NLHF document will be used to form an action plan and guide decision makers and stakeholders in strategic planning.[3]

The creation of a comprehensive framework has the potential to improve the respiratory health of Canadian women and men from prevention to diagnosis, management and treatment. The framework also seeks to address some of the health challenges facing diverse sub-populations of Canadians. For example, the documents produced during the framework development process specify the need to "[address] the needs of vulnerable populations," and consistently identify First Nations persons, youth and immigrants as important sub-populations for respiratory health initiatives.[4] The four key strategies in the framework document,[1] which deal with everything from health promotion and disease detection to policy and research, indicate that actions must aim to not only improve overall health, but also the disparities between Aboriginal and non-Aboriginal populations.[3] The steering committee has identified many research- and practice-based issues, such as the importance of examining relationships between respiratory health, vulnerable populations and environmental factors, and the need to improve provider-patient support and increase the use of spirometry as a diagnostic tool.[5,6]

Developing a national framework is a significant challenge, given the wide range of acute and chronic respiratory conditions affecting Canadians. These include diseases as varied as asthma, tuberculosis, sleep apnea, pneumonia, influenza, COPD and lung cancer, each of which have

i (1) health promotion, awareness and disease prevention; 2) disease detection and management; 3) policy, partnerships and community/systems support; 4) research, surveillance and knowledge translation

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unique causal, diagnostic, management and treatment issues. Furthermore, these four issues vary between women and men, and among sub-populations of women and men. Hence, the sex and gender issues associated with respiratory disease and health need to be explicitly addressed in the framework in order to have a beneficial and equitable impact for *both* women and men. However, a preliminary analysis of the existing framework documents[2-5] indicates that sex and gender factors, and diversity related differences and influences have not been sufficiently identified, and that sex and gender analysis is not identified as a key analytical tool for strategic planning. In response to this lack, this article examines some of the respiratory health needs of women to highlight how these omissions within the current framework may fail to capture sex- and gender-based differences between women and men.

Why integrate a sex and gender lens?

If significant improvements in lung health are to be made, sex and gender analysis must be an integral part of planning and program initiatives. Sex- and gender-based analysis (SGBA) is a tool that promotes consideration of a range of issues related to both the research process and the application of knowledge in program or policy development activities such as the NLHF. An SGBA is recommended by Health Canada's Women's Health Strategy,[6] and is also integrated into the work of the World Health Organization (WHO).[7] Using such an approach helps to improve our understanding of how the influences of sex (i.e. biological) and gender (i.e. social and cultural aspects) determine health and disease. The effectiveness of how we design and implement sex- and gender-sensitive policies and programs is partially determined by such analyses.[8] Utilizing SGBA would allow the national strategy to address the unequal distribution of disease among women and men and among sub-populations of women and men, including Aboriginal groups and those with low incomes.

The reviewed documents underpinning the NLHF[2-4,5] fail to clearly or consistently articulate a sex- or gender-based approach; nor do they indicate whether sex or gender has informed the development or implementation processes. Occasionally, the differences between women's and men's respiratory health needs and issues are discussed. Importantly, the increasing smoking rates in women are identified as a timely issue,[4,5] as is the growing prevalence among women of COPD and lung cancer, in part due to the relative lag in women's smoking compared to men.[4] In addition, pregnant women are cited as an important population when creating cessation programs.[5] Yet the mention of women in the NLHF documents is additive and sporadic in comparison to other populations such as youth, First Nations people and immigrants,[3,4] and the need to examine the specific health needs of women and men and sub-populations of women and men is not consistently identified. Overlooked in the NHLF is the fact that all populations are *gendered*, and their health concerns need to be addressed accordingly.

Sex and gender influences on lung health

Numerous sex- and gender-based influences and factors must be considered to develop a framework that addresses respiratory health needs. To illustrate this point, we consider some of these needs, focussing on the context of women's respiratory disease prevention, diagnosis and treatment issues. For example, many respiratory diseases affect women and men disproportionately. Women have higher rates of asthma, COPD is increasingly becoming a woman's disease, and mortality rates for lung cancer have been increasing among women in Canada since 1987, yet decreasing among men.[1] There are also more lung cancers among women who have never smoked, compared to men who have never smoked.[9,10] Furthermore, certain sub-populations of girls and women, including low socio-economic groups and non-white minorities, have disproportionately higher rates of respiratory disease. Non-white and low-income women tend to have less access to health care resources and suffer more often from disease and disabilities.[11,12]

Tobacco use is a key factor in the development of respiratory disease. Gendered patterns of smoking and exposure to smoke, and biological, hormonal and genetic factors overlap and influence women's susceptibility to respiratory diseases.[13] Estrogen may influence the metabolism of cigarette smoke, resulting in increased damaging effects.[10,12,14-16] Evidence shows that women who smoke less than men show similar levels of impaired lung function, and smoking decreases women's lung function more than men's.[12,17,18] Meanwhile, tobacco marketing has been gendered, effectively and increasingly targeting women, portraying smoking as glamorous and as a method to stay thin.[19,20] The industry has also developed gender-specific tobacco products. Many women have been marketed "light" cigarettes with higher yields of N-nitrosamines, which may be partially responsible for the increased lung cancer rates in women.[12] Second hand smoke also impacts women differently than men, given the lag in overall smoking trends between men and women is resulting in more non-smoking women living with men who smoke.[19,21]

There are also sex and gender issues associated with diagnosis. Women and men report different symptoms and women develop COPD at a younger age.[12] Women are also less likely to report sputum production than men, due to gendered norms and ideals.[22] In addition, women are often under-diagnosed or misdiagnosed for certain diseases, due to these differences in presentation as well as gender bias in the health system. For example, women with COPD are more often diagnosed with asthma than men.[13,23] Moreover, even when women and men present the same symptoms, providers may not interpret symptoms in the same way.[24]

In general, compared to men, women with respiratory diseases tend to report more hospitalizations, more limitations in activity and higher rates of anxiety and depression associated with respiratory diseases.[1,23,25-29] Changes in physical appearance associated with COPD and lung cancer may be especially troubling for women, who are encouraged to meet gendered social standards of beauty.[28] Finally, pulmonary

rehabilitation has been shown to be more effective for men over time.[22] All of these factors shape women's and men's lung health from prevention to treatment and need to be addressed and included within the planning stages to produce a framework that will significantly improve women's and men's respiratory health.

Conclusion

The NLHF can significantly improve the dissemination and uptake of knowledge related to respiratory health by drawing links between sex- and gender-specific research in both tobacco use and exposure, as well as respiratory health and disease. There is a clear need for the integration of spheres of knowledge on tobacco, gender, and respiratory disease.[12] The highest rates of mortality are associated with diseases that are primarily associated with smoking or smoke exposure, such as COPD and lung cancer. There is inconsistent evidence regarding gender differences in cessation.[ii] Regardless, women and men do smoke for different reasons and have different cessation patterns.[20] One potential strategy for addressing some of these issues is the formation of a NLHF working group on sex, gender and diversity issues, which could include researchers and decision makers in lung health, women's health, men's health and tobacco use and prevention. Connections must be strengthened between research, programs and policy so that emerging sex- and gender-specific findings are effectively translated to health care settings and decision makers.[40] By addressing these and other sex- and gender-related factors, the NLHF could lead the way in effectively responding to *all* "vulnerable" groups.

The identification of sex- and gender-based analysis as a key analytic tool would encourage researchers, decision makers and other stakeholders to account for these differences. In sum, there are different reasons why women smoke, as well as varying experiences of care and treatment for respiratory disease, both compared to men and among sub-populations of women. We have discussed some of the unique respiratory health concerns of women in particular to make a case for a more detailed, consistent and mainstreamed need for a sex and gender lens to guide the NLHF and action plan. The full and comprehensive implementation of a sex and gender analysis would also necessitate an exploration of the unique respiratory health needs of men, and contribute to a systematic assessment of gendered responses aimed at men. The NLHF can seek to improve the respiratory health of all groups, through the creation of initiatives to support and encourage further sex and gender-based research and interventions. Although very little research has examined specific respiratory health issues for sub-populations, such as people on low incomes or of particular ethnic groups, the NLHF can address and respond to these issues by utilizing an SGBA to encourage thought on women in Canada and steer Canada toward future sex-, gender- and diversity-based research, programming, policy and analysis.

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